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IDENTIFIERS	*Pennsylvania

ABSTRACT

This final report discusses the activities and outcomes of a 4-year federally funded project designed to provide effective practices in the delivery of educational services to Pennsylvania children and youth with deafblindness from birth through 21 years of age and to their families and service providers. Outcomes of the project included: (1) increasing the capacity of local educational agencies, intermediate units, and community agencies to deliver effective consultation and appropriate technical assistance in a timely manner to children who are deafblind through accurate identification; (2) creating a systematic approach for parent involvement in planning and developing coordinated, comprehensive, and longitudinal service plans for their child which include early identification, appropriate educational program, transition, assistance with competitive or supported employment, assistance with residential options for independent living, and placement of their child in the least restrictive environment; (3) ensuring ongoing coordination of services among state and national agencies responsible for providing services to children with deafblindness; and (4) increasing the utilization of effective and age-appropriate practices that promote the inclusion of children with deafblindness. The report discusses activities, challenges and solutions, and implications for practice. Appendices include participant letters of support, advisory council membership, sample activities, and products. (CR)

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ED 436 920

PENNSYLVANIA DEAFBLIND PROJECT

FINAL GRANT REPORT

Submitted to the United States Department of Education,
Office of Special Education Programs

October 1995- September 1999

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Office of Educational Research and Improvement
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> *"Alone we can do so little;*
> *together we can do so much"*
> *...Helen Keller*

A Message from the Pennsylvania Deafblind Project

The success of the Project is due to many partnerships. We have learned much wisdom from the families of children who are deafblind. Other children, especially brothers and sisters, have contributed to the lives of children who are deafblind. Colleagues from the Instructional Support System of Pennsylvania, administrators and educators from early intervention agencies, schools, school districts, and Intermediate Units, other service providers, and our Advisory Council have also shown incredible commitment to children who are deafblind. Most of all, children who are deafblind continue to show us new insights into learning.

We thank you and will continue to serve you, as we all work together to improve the quality of services for children who are deafblind.

Sincerely,

Project Director: *Fran Warkomski*

Project Coordinators: *Juli Baumgarner, Mary R. Frey, Jeanne Gardier*

Family Liaisons: *Molly Black, Stacy Gerlach, Susan Shaffer*

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Pennsylvania Deafblind Project
Final Grant Report
1995-1999

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Pennsylvania Deafblind Project

PENNTECH/Lancaster-Lebanon Intermediate Unit 13
6340 Flank Drive, Suite 600
Harrisburg, PA 17112

Executive Summary

Scope of the Deafblind Project

In 1995, the Commonwealth of Pennsylvania assumed full leadership and support for the technical assistance and training needs of families, educators, and service providers of children who are deafblind. Previously, PA had been a member of a multistate project. Although many resources existed in the multistate project, it was critical that we embed our services within the early intervention and educational systems of PA. This also occurred at an exciting time of efforts to enhance local and state capacities, allowing for multilevel systems changes. We were able to model for our constituents the concept of "growing" our own resources, while keeping a careful eye on current effective practices. Children and youth who are deafblind or at-risk for deafblindness (hereafter referred to as "children who are deafblind") need specialized and intense educational planning and services. Project goals were designed with these needs in mind.

The original goals of the PA Deafblind Project were implemented as planned. State and national initiatives also were addressed throughout the four years of this Project, resulting in additional activities and partnerships.

The reauthorization of the Individuals with Disabilities Education Act (IDEA '97) provided many opportunities to improve services for children who are deafblind. We continue to contribute to the preparation and delivery of IDEA '97 training and resources across the Commonwealth. In particular, issues around learning media assessment, assistive technology, cultural issues of the deaf community, and positive behavior support have been addressed through development of resource materials, and information, training, and technical assistance for families, educators, and service providers of children who are deafblind.

The Governor's Initiative related to Education and Individuals with Disabilities set priorities for low incidence populations, including deafblindness. Activities of the Project were integrated with goals of the Governor's Initiative, allowing us to impact on a broader audience, policies, and procedures. The Governor's Initiative supports statewide training for individuals who serve children with sensory impairments, including on interpreter training, learning media assessment, and literacy.

In 1999, Pennsylvania was awarded a State Improvement Grant from the United States Department of Education. The Project has collaborated with the Comprehensive System of Personnel Development and the State Improvement Plan regarding both preservice and inservice training, in order to improve the quantity and quality of personnel who serve children with disabilities.

Alex, eight years old, attends a first grade classroom at his neighborhood school. He understands the organization of his day by using a picture schedule system. He participates in classroom activities with adaptations such as switch activated tape recording of the Pledge of Allegiance, a rubber stamp to label his artwork and classroom papers, and stars on the building walls to help him trail to his classroom. He recently received his first invitation to a classmate's birthday party.

Prior to attending his neighborhood school, Alex was bussed to a program in another county. He received many services at this program, and learned many new skills. A timeline was developed to bring Alex back to his home school. Person centered planning, discussion and training with school personnel and administrators, and a team approach have contributed to his success. Most importantly, Alex is regarded as a true member by the children and adults at his school.

Mission and Goals

The mission of the Pennsylvania Deafblind Project is to build capacity to ensure success for all infants, young children, students and youth who are deafblind, or at risk or deafblindness, in the context of local schools and communities.

This mission is congruent with the mission of the Instructional Support System of Pennsylvania.

Five key goals align with the mission of this project:

I. To increase the local capacity of local educational agencies, intermediate units, and community agencies to deliver effective consultation and appropriate technical assistance in a timely manner to children who are deafblind.

The purpose of this goal included the timely and accurate identification of children who are deafblind, including those at-risk for deafblindness. The number of children identified as deafblind has been commensurate with expected numbers, based on the population of PA children. Accuracy in identification has also increased over the four years, as a result of efforts to ensure that assessment of vision and hearing is done in a timely manner. Identification of children who are deafblind has impacted on the delivery of effective practices.

II. To create a systematic approach for the level and equality of parent involvement in planning and developing coordinated, comprehensive and longitudinal service plans for their child to include: early identification, appropriate educational program, transition, assistance with competitive or supported employment, assistance with residential options for independent living, and placement of their child in the least restrictive environment.

The intended outcome of this goal focused on increasing the participation of family members in the development of plans for their children. This goal was accomplished with a variety of training strategies, provision of information, and parent-to-parent support. As a result of the Project activities, families have increased their impact on the education and support of their children.

III. To ensure ongoing coordination of services among the Pennsylvania Department of Education, the Pennsylvania Department of Public Welfare (the state's lead agency under Part H of IDEA), and other state and national agencies responsible for providing services to children with deafblindness.

As intended, Project activities were conducted in partnership. As a component of the Instructional Support System of Pennsylvania, the Project has enriched our services by utilizing other resources. In turn, the Project provided important information and awareness of the educational needs of children who are deafblind.

IV. To increase the utilization of effective and age-appropriate practices that will promote the integration of children with deafblindness with children with other disabilities and without disabilities.

As intended, the outcome of this goal is an increase in the number of children being served in the least restrictive educational setting, and an increase in participation in school community activities.

V. To evaluate the activities of the project in order to increase accuracy of meeting needs of children who are deafblind and their families and to insure ongoing quality of service provision.

The project conducted continual evaluation of project activities and the needs of children who are deafblind and their families. Extensive evaluation of the needs of educators and service providers was also integrated with project evaluation.

Key activities to meet our goals:

- Child count
- Joint planning and delivery of training
- Preservice, inservice, workshop, and guided practice activities to promote inclusion of children who are deafblind
- Data collection regarding satisfaction and impact of project activities; ongoing needs

Key strategies related to these activities

- Accurate and early identification of children who are deafblind
- Collaborative, interagency, multilevel technical assistance
- Varied methods of delivery of technical assistance and training, including follow along activities.
- Ongoing monitoring of the efficacy of the project, utilizing data to adapt for current and future needs

Conclusion

A comprehensive approach has allowed us to meet ongoing needs of those we serve, while enhancing the ability of agencies and schools to cultivate their own resources. Primary roles and responsibilities of Project staff are to provide support, information, and training on specific educational strategies to ensure success of children who are deafblind. Only through partnerships can we provide for effective educational programming for children who are deafblind.

"The Project has touched the hands of my husband and myself, giving us the power of information to touch our son and his teachers, thereby giving him the tools to one day reach out and touch the world in his own special way."- from a parent

Context

The Commonwealth of Pennsylvania is a large and diverse state consisting of 501 school districts, 29 intermediate units (regional education service agencies providing services to Commonwealth schools and communities) and 45 county-based Mental Health/Mental Retardation programs and other community agencies.

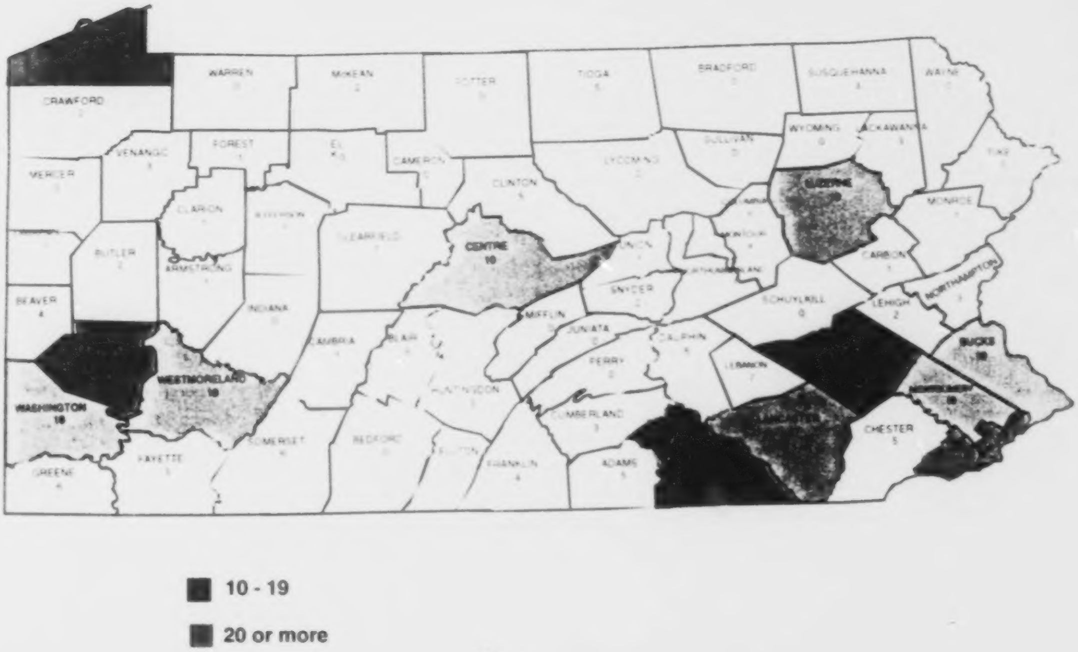
With 474 children in Pennsylvania currently identified as deafblind, the Project has significant responsibilities to insure appropriate services are provided to these children and their families. Pennsylvania is ranked fifth in the number of children identified as being deafblind on the census, as well as population.

Table 1: Number of Children in Pennsylvania

Children	1995-96	1996-97	1997-98	Ranking in U.S.
Total Number	1,786,393	1,803,157	1,814,081	
Special Education	210,443	214,928	222,598	
Early Intervention	15,596	15,585	15,879	
Deafblind	521	534	474	**Fifth**

Children who are deafblind are found in every region of the Commonwealth, from densely populated urban areas to sparsely populated rural areas. Recognizing the diversity of Pennsylvania, activities were provided to enhance the state's capacity to improve the quality of services provided to children with deafblindness throughout Pennsylvania. The Instructional Support System of Pennsylvania (ISSP) is the technical assistance and training branch of the Pennsylvania Department of Education (PDE), Bureau of Special Education (BSE). Early Intervention and Technical Assistance (EITA), a component of the ISSP, is the technical assistance and training branch for early intervention for the PA Departments of Public Welfare (birth to three years), Education (three to five years), and Health (birth to five years).

CHILDREN IDENTIFIED ON DEAFBLIND CENSUS BY COUNTY


CRAWFORD
WARREN
McKEAN
2
POTTER
TIOGA
BRADFORD
SUSQUEHANNA
WAYNE
VENANGO
FOREST
ELK
CAMERON
CLINTON
LYCOMING
SULLIVAN
WYOMING
LACKAWANNA
PIKE
MERCER
CLARION
JEFFERSON
CLEARFIELD
CENTRE
10
LUZERNE
MONROE
BUTLER
2
ARMSTRONG
UNION
MONTOUR
NORTHUMBERLAND
CARBON
BEAVER
4
INDIANA
SNYDER
SCHUYLKILL
0
LEHIGH
2
NORTHAMPTON
MIFFLIN
JUNIATA
DAUPHIN
CAMBRIA
BLAIR
PERRY
LEBANON
BUCKS
WESTMORELAND
10
HUNTINGDON
WASHINGTON
10
CUMBERLAND
MONTGOMERY
CHESTER
5
SOMERSET
BEDFORD
FULTON
FRANKLIN
4
ADAMS
5
FAYETTE
GREENE
4
■ 10 - 19
■ 20 or more

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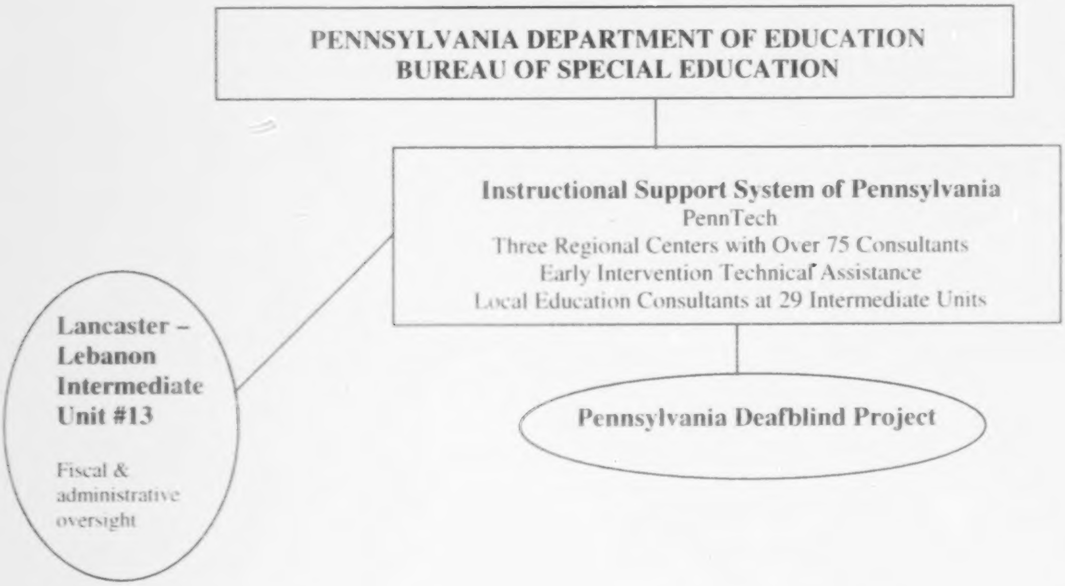
BSE operates three Instructional Support Centers in Pennsylvania-east (EISC), central (CISC) and west (WISC)-each serving a geographical third of the state. Each center also houses a number of different projects which have state-wide responsibilities, such as Distance Learning. Each Center's consultants work with designated Local Education Agencies (LEA), Intermediate Units (IU) and county programs. As a member of the ISSP, the Project therefore has access to numerous early intervention and education consultants across the state and to partnerships with numerous state, regional and local organizations.

Organizational Chart


PENNSYLVANIA DEPARTMENT OF EDUCATION
BUREAU OF SPECIAL EDUCATION
Instructional Support System of Pennsylvania
PennTech
Three Regional Centers with Over 75 Consultants
Early Intervention Technical Assistance
Local Education Consultants at 29 Intermediate Units
Lancaster – Lebanon Intermediate Unit #13
Fiscal & administrative oversight
Pennsylvania Deafblind Project

Throughout the four years of the grant, the PA Deafblind Project had one fulltime education consultant housed at the Western Instructional Support Center, and one fulltime education consultant housed at the Central Instructional Support Center. During the last year of the grant, one education consultant was hired part time in the northeastern part of the state. The Project Director was provided in-kind from the ISSP.

Over the four years of the grant, several parents have been hired for a varying number of hours per month as family consultants or parent liaisons. One halftime support staff assists the Project and fiscal support staff have been provided in-kind from the ISSP. The Project has also received countless hours of in-kind support from ISSP consultants, especially those involved with vision impairment, hearing impairment, transition-to-adult life and assistive technology. Several times a year, out-of-state consultants were contracted to provide specific training and technical assistance.

PennTech/Lancaster-Lebanon Intermediate Unit 13 provides fiscal and administrative oversight for the Pennsylvania Deafblind Project through the Instructional Support System of Pennsylvania.

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Goal 1

To increase the local capacity of Local Education Agencies, Intermediate Units, and Community Agencies to deliver effective consultation and appropriate technical assistance in a timely manner to infants, toddlers, children, youth and young adults and their families.

The intended outcome of this goal was a comprehensive system of service delivery at the local level, giving timely access to quality services for children who are deafblind.

This goal was accomplished by:

Continuous data collection and monitoring of the status of children who are deafblind.

- Provision of materials about screening and identification of sensory impairments
- Generation of single student reports and intermediate unit area reports based on census data and provided back to the reporting agencies
- Sharing information packets about Project services and resources to families, educators, and service providers of newly identified children who are deafblind
- Availability of tollfree phone number, voice mail, electronic mail for Project
- Inclusion of the census form and related information on the Project's webpage http://www.cisc.k12.pa.us which may be downloaded
- Identifying at least one local contact person for each child who is deafblind

Planning, implementing and evaluating training and technical assistance activities

- Responding to training and technical assistance requests and developing plans in collaboration with the Instructional Support System of Pennsylvania and related agencies
- Building training and technical assistance around the people who are essential to lives of children who are deafblind, guided by their needs and strengths
- Jointly training early intervention and early childhood service providers on effective practices for young children who are deafblind
- Frequent consultation, guided practice and on-site visits with child educational teams including family members and community personnel
- Emphasizing transdisciplinary teamwork and linking persons back to local supports
- Development and implementation of systematic observation and child-centered action plans
- Co-development and training of IDEA '97 module
- Delivering training based on local identified needs regarding effective education practices
- Dissemination of materials and information to schools, intermediate units, and service providers

"The education consultant has brought the team together. She has provided training to the preschool staff and loaned resource materials to staff and family. I can go to her for advice and decide how to approach the school. She has been a great help in helping us to focus."

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Challenges and Solutions

When children who are deafblind reach transition points, it may be difficult to track them. This is because they are sometimes not reported on the deafblind census by the receiving agency, intermediate unit or school district. The points generally tend to be for those who are moving from early intervention programs (provided through PA Department of Welfare) to preschool programs, those who reach the local school district's age of "beginners", and those entering high school. Since the children may receive educational services from a number of state departments, more effective communication among sending and receiving entities needs to be in place. In the past, the Project was able to work with the statewide child count reporting systems to locate children who were previously identified but not reported the following year, in order to follow up locally.

The PA education and early intervention statewide child count systems have changed. Individual child information is not longer identifiable at the state level, only locally. Information on the deafblind census is maintained on a database at the Project and may be easily changed at any time during the year. The Project now sends out a single page census report per child in the spring and a reminder postcard in the fall to the identified local point of contact for each child. Once the sending agency knows where child will be transitioning to or if there are other informational changes, the agency can easily revise the report and forward to the Project. In addition, the Project provides agencies, programs, intermediate units and school districts with a local group report to assist them in keeping track of all those identified within their region. An added bonus is that it allows the Project to discuss the local impact of this low incidence population on their staff and staff development.

With the large numbers of children who are deafblind in PA, the Project relies on local educators and service providers to provide accurate identification of children by determining their eligibility and completing accurate census forms. Nearly 30% of the initial census forms are returned with inaccurate or incomplete data or with inconclusive hearing and/or vision assessments

Level of Hearing Impairment/Deafness

Tested – Results Non-conclusive	53
Further Testing Needed	42

Level of Vision Impairment/Blindness

Tested – Results Non-conclusive	20
Further Testing Needed	31

Some of this is due to the fact that each child's census form may be completed by a different professional, for example, a classroom teacher, a vision consultant, a supervisor of special education, or a preschool director. There is no statewide policy but local discretion about who is to complete the information or is designated as the local contact person. In turn, this leads to the need for the Project to provide information and technical assistance regarding eligibility and accuracy to a variety of persons.

Although PA reports the census information once a year to the United States Department of Education, the Project continuously updates census records. Additional information, strategies and resources regarding functional assessments for vision and hearing were developed. All this was mailed out with each child count census form or upon request. Project staff made personal contacts and conducted follow up phone calls to clarify and increase the accuracy of the reported information or to respond to questions. When staff found themselves answering the same questions repeatedly, a question and answer sheet was developed and distributed.

In addition, technical assistance and training was provided in collaboration with Instructional Support System of Pennsylvania consultants at regional meetings of supervisors of consultants with early intervention, blind/visually impaired, deaf/hard of hearing, and service coordinators. Information on the Project and the census was included in statewide mailings to Instructional Support System of PA consultants and all administrators of county programs, intermediate units and school districts. The Project coordinated with the Instructional Support System of Pennsylvania to update joint mailing lists and resource directories. Staff presented at statewide, national and international conferences.

The Project added a PA Page to the federal census form annually, using an optional questionnaire. In order to help the Project identify specific needs, questions were focused on a different topic each year, such as communication modes used by children and staff, behavioral concerns, assistive technology, socialization, and inclusion opportunities. Always, there is space for the local contacts to list other technical assistance requests which are then followed up on an individual basis by Project staff.

Primarily focused on the staff at the local education agencies, school districts and county programs, some of the Project materials such as workshop brochures or information updates included educational jargon and systemic concerns, rather than being personalized or "user friendly." Related to this issue are the difficulties for schools to find substitutes and for parents to find child care so that they may attend large statewide or regional conferences which may be far from home and last one or several days. With the large number of children who are deafblind, along with their education teams and families, it can be difficult for Project staff to be involved on an individual or more personalized level.

The Project has shifted its focus for technical assistance from large state and regional trainings to more individualized support as defined through locally developed action and technical assistance plans. Staff coordinated resource sharing among relevant agencies to make an extensive lending library of materials and assistive technology equipment available at no cost to PA families and educators.

In collaboration with parents, especially those on the Advisory Council, the Project developed and distributed "family-friendly" flyers about Project services. The Information Update became more invitational by considering the "one child/one family/one teacher" approach. Information Sheets were collaboratively developed with children and family members to tell a "first-person" story. Birthday cards were sent out to each child during the month of the birthday.

"Thanks for sending my daughter a birthday card. She is doing fine. ***Here is a photo for the Project's album."***

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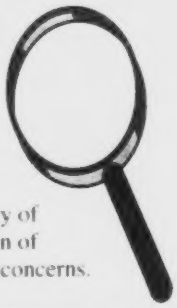
For more individualized support, the Project began small study groups held via conference calls.

> *" We don't always talk about the assigned reading but what is going on in our lives with our child who is deafblind. This is as important as what we are learning through the readings."*

To cut down on the need for substitutes, child care or travel, the Project provided phone cards for the family liaison to make parent-to-parent phone calls. Quarterly meetings of the Advisory Council and state transition teams were held via local videoconference links or conference telephone calls.

Implications for Policy, Practice, and Research



For families and children to have access to and receive quality services in a timely manner requires a statewide comprehensive systemic plan, balanced with increased local capacity to serve one child/one family/one team appropriately. Because PA has a statewide improvement grant for partnerships and collaborates through the Instructional Support System of Pennsylvania to serve all children with special needs, care must be taken to continually address the needs of the population of children who are deafblind, their families and service providers across the systems. While PA maintains an accurate count of these children through the deafblind census, there is not always the same recognition to the category of deafblindness on the statewide special education child count. This in turn affects the provision of specific staff development and family involvement activities relevant to deafblind issues and concerns.

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Goal II

To create a systematic approach for the level and equality of parent involvement in planning and developing coordinated, comprehensive, and longitudinal service plans for their child to include: early identification, appropriate educational program, transition, assistance with competent or supported employment, assistance with residential options for independent living and placement of their child in the least restrictive environment.

This goal was implemented to ensure that parents and families are actively involved in their child's IFSP and IEP development and implementation process. Project consultants and family liaisons accomplished this goal by providing statewide mechanisms, balanced with individual and local mechanisms, in order to systematically involve families.

The Project trained and compensated three parents of children who are deafblind to work a number of hours per month for the Project as family liaisons. In addition, parents were either regular members or ad hoc members of the Advisory Council for the Deafblind and the Community and State Transition Team Partnerships for Children Who Are Deafblind.

> Family liaisons have provided parent-to-parent support by contacting parents of newly identified children and keep in touch with parents related to specific topics. They act as liaisons between the Project and local or regional concerns and issues.
>
> Family Consultants have co-planned and co-presented training especially at regional and statewide family learning days and weekends. They make phone calls several weeks after a major activity to discuss the continued impact on the family from the information learned at the activity.
>
> A number of parents and students have offered their personal perspectives through first person stories on assistive technology, communication strategies, and surfing the web.

"The Project's benefits are not always clear to a new family. Sometimes listening to another parent sharing their experiences, as well as explaining about the technical assistance provided to them by the Project makes all the difference in their understanding. At the urging of a Family Consultant, several new families attended regional day events sponsored by the Project. Parent – to- parent support is a unique component that is provided by the Project."

The Project supported families' involvement in educational planning through team-based technical assistance. The Project's model was family focused, person-centered, and based on the outcomes of effective educational practices and community membership.

> Parents were involved in development of IFSP and IEP plans via consultation with Project staff before the IFSP and IEP meetings to discuss specially designed instruction, integrated goals, future directions, communication, and adaptations and modifications.
>
> Families were given access to training opportunities related to most effective practices in deafblind education through regional Family Learning Days, state-wide

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Family Learning Weekends, Summer Institutes and all inservice activities offered by the Project, including those offered as teleconferences. For a period of time, the Project held regularly scheduled conference calls with the regional vice-presidents of the PA Parents for Deafblind Group. Time was scheduled on Learning Retreat Weekends for Parents PA for Deafblind Group to meet.

Parents have the availability of family-to-family support and participant lists from workshops they have attended. Since the Project had parental permission to contact the majority of families, regular access to information was frequently provided through Information Updates and Information Sheets, targeted mailings, web page information, and materials from an extensive lending library. Updates include information on disability-related support groups, web-sites, conferences and workshops.

Study groups have been in place for the last two years. Coordinated by a family liaison and educator, the study groups were held monthly via conference calls on specific topics or books, such as Hand in Hand. At family learning weekends or through first person stories, parents shared the impact on their child and other family members of what they learned through the study groups.

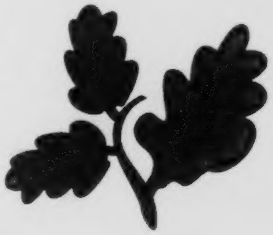
"This study group has helped me apply the information learned to my child's IEP. I am better able to participate as a team member because of the knowledge that I bring to the table."

"Parents are so happy for the information. It is so nice to have families call with good news, say how pleased they are with the information and technical assistance, versus hearing from them only when they have challenges." – from Advisory Council member.

Family Learning Weekends and Days

The statewide weekends were held annually in a central location at minimal cost to families. Activities were set up for all the children, along with specific sibling sessions, parent only sessions and family sessions. A notebook was provided to each family with all the session information, child care schedules, networking contact list, Project information and feedback sheets. Booklets written by or about the children were published and distributed at each weekend.

Regional Learning Days were held in the western and eastern parts of the state each year, primarily for those families unable to attend the annual weekend although any family was welcomed. Families were asked to invite any of their child's team members to join them. The themes complemented or provided additional training to the annual learning weekends.



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Themes of Family Learning Weekends

"Dreamcatchers"

The theme was person-centered planning. Families were taught a variety of models such as MAPS and PATH. They had the opportunity to share their dreams and nightmares in a comfortable atmosphere. One of the speakers was a parent with a child who had been through the process. Participants were given the opportunity to try the process and to discuss how to integrate this information into their child's IEP/IFSP and CER process.

"Making Connections: Hand in Hand in Hand"

The theme was identifying and linking into local community resources and accessing natural supports. Families decided what was important to them to support their child as an individual and themselves as a family. They learned how to find and contact community resources and how to share relevant information about their child to community members.

"Diversity: Colors of the Rainbow"

The theme was diversity of communication, interaction, mobility, behavior, and preferences. All the different ways that children with deafblindness move, communicate, socialize, behave, and play were explored. Families discussed how to share what they learned with extended family and IFSP/IEP team members.

"Together We're Better: Learning Through Play and Humor"

The theme was leisure and fun. Families were given ideas of how to reduce stress and to share the work of having a child with deafblindness. They learned more ways to have fun as a family and include their child with deafblindness more easily in family activities.

Challenges:

One of the initial challenges of the learning weekends was that the Project ran such separate activities for parents and children that neither group understood what the other was learning or experiencing. Activities were planned like a typical educator conference with one-to-three hour sessions and 15 minute breaks, an hour for meals. Many of our families had never met an adult with deafblindness.

Solutions:

Now we plan time for the information from the sibling sessions to be shared with parents. We offer parallel activities so each group has the opportunity to do something similar. For example, we had assistive technology equipment set up and demonstrated by students and educators. During the morning, the children tried the equipment. Siblings had a chance to touch and experiment with assistive technology equipment that their brother or sister may use. In the afternoon, the parents tried the equipment. The evening activity allowed time for the whole family to show off and share with each other what they learned to do.

Based on feedback from parents, we changed our schedule to be more "family – friendly" with longer break and mealtimes. Parents are on the planning committee with Project staff . Time is planned in the schedule for parents to go see what their children are doing in the activities.

Several adults with deafblindness were invited to join families and staff for discussions with families at the weekend. Also, the Project had two consumers on the Advisory Council.

Guided practice and sharing experiences with families are important enough to schedule designated time during the weekend. The informal discussions among families and staff during the weekends were as valuable as the planned sessions.

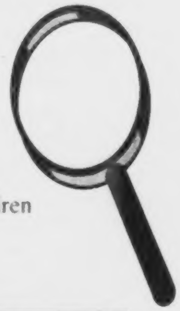
Learning Awards

Learning Awards have been a means for the Project to provide additional training and support to families and extend Project resources. We sponsored the participation of parents in several national conferences and courses, as well as purchased materials for them.

Cornelia Delange National Conference	1 parent
National Conference on Deafblindness	4 parents
National CHARGE Conference	2 parents, 1 child
NFADB/NTAC Summer Conferences	8 parents
Foundations of Deafblind Education course	3 parents, 8 educators
Sign Language Classes	4 parents, 1 sibling
Assistance with Summer Camp	1 family
"Hand in Hand..." set of materials	12 parents
Books, videotapes, INSITE materials	12 parents, 3 educators
Creating Collaborative IEPs: A Handbook"	8 parents
Special Children, Challenged Parents"	27 parents

Implications for Policy, Practice, and Research

Families must be involved in all aspects of the Project as "touchstones." Information and support so that families can effectively interact and share what they have learned with others also must be embedded in all Project activities. Continual assessment of ways to build family capacity can be accomplished through a variety of strategies, including parent-to-parent contact. It is important to continue to hold national level workshops for parents and families to interact and learn together while connecting those families back to their state resources. Bringing together adults with deafblindness together with families of younger children with deafblindness will build mechanisms for supporting and mentoring families.



Goal III

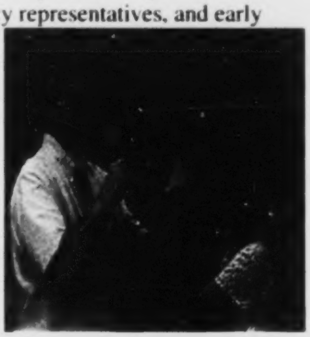
To ensure ongoing coordination of services among the Pennsylvania Department of Education, the Pennsylvania Department of Public Welfare (the state's lead agency under Part H of IDEA), and other state and national agencies responsible for providing services to children with deafblindness

This goal was achieved across Project activities to increase the impact and quality of services for children who are deafblind.

This goal was accomplished by:

- Establishment and maintenance of an Advisory Council with membership from many stakeholder groups (e.g., families, consumers, school administrators, adult agency representatives, and early intervention representatives).

- Membership and contributions of Project personnel to many other initiatives and collaborative efforts



Project personnel have assisted in planning and presenting at the annual meeting of National Project Directors' of State and Multistate Projects, have presented at state and national workshops conferences and many local workshops.

Project personnel were members of several statewide projects (e.g., Positive Behavior Support, Quarterly Institutes on Literacy for Low Incidence/Sensory Impairments, Alternate Assessment Committee).

The Project has contributed to the development of many materials and resources, which are used in state and local training and technical assistance. This has allowed us to increase the awareness of the needs of children who are deafblind, and to impact on the quality of educational programming for those children.

"The college recognizes and respects the efforts made thus far by you and members of your organization to improve services for the target populations." -from an assistant dean of the PA College of Optometry

Selected examples of materials and resources developed jointly with colleagues, and which have included a focus on children who are deafblind:

"When Hearing Loss and Retinitis Pigmentosa Occur Together: Meeting Educational Needs" (Teleconference 2/95)
"What Are All These Adults Doing in My Classroom?" (Teleconference 11/96)
IDEA'97 Training Notebook and Resources (Fall 1997)
First Glance Newsletter "How Pennsylvania Is Addressing the Educational Needs of Students with Sensory Impairments/Low Incidence" (7/98)
"Did You Know: Low Incidence Disabilities Fact Sheet" (7/98)
Quarterly Institutes on Literacy for Low Incidence/Sensory Impairments (1998-1999)

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MATERIALS DEVELOPED

Information Sheets

- Behavior Issues in Children With Multiple and Sensory Impairments
- Considerations in IEP Development for Children Who Are Deafblind
- It Begins With Communication
- Letter From Janna
- Preferred Activities and Motivators
- Questions and Answers About the Pennsylvania Deafblind Project:
  - For families
  - For educators
- Questions and Answers about the Pennsylvania State and Community Transition Team Partnership for Individuals Who Are Deafblind
- Questions and Answers About the Deafblind Census of Pennsylvania
- A Story About Alex
- A Story About Zenola
- Surfing the Web
- Tips for Students With Usher's Syndrome
- If You Need an Evaluation of a Student's Vision . . .
- If You Need an Evaluation of a Student's Hearing . . .
- Fact Sheet: PA Deafblind Project
- "Family Friendly" brochure
- Strategies For Successful Participation in Community Activities
- Connections I'd Like to Make (April 1997 FLW) children's booklet
- Request for Resources
- Here are Some Good Ideas We Caught . . .
- I Dream I Want to Catch (June 1996) children's booklet
- Welcome packets to "new" families on census
- Children of the Rainbow Stories (June 1998 children's booklet)
- Together We're Better Stories: Learning Through Play and Humor (June 1999 children's booklet)

INFORMATION UPDATE

- Issue 1, Spring 1996
- Issue 2, Summer 1996
- Issue 3, Fall 1996
- Issue 4, Spring 1997
- Issue 5, Summer-Fall 1997
- Issue 6, Winter 1997
- Issue 7, Fall 1998
- Issue 8, Spring 1999
- Issue 9, Fall 1999

➢ Provision of information and resource materials related to the unique educational needs of children who are deafblind

A resource database lists materials, which are available for loan to families, educators, and service providers.Information Updates and Fact Sheets are distributed on a quarterly basis. Brochures and information about other relevant training opportunities and resources are forwarded on a frequent basis.

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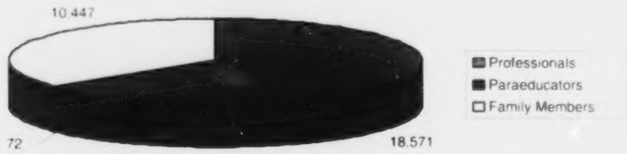
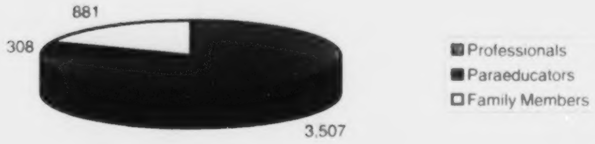
TECHNICAL ASSISTANCE AND TRAINING ACTIVITIES

Pennsylvania Deafblind Project

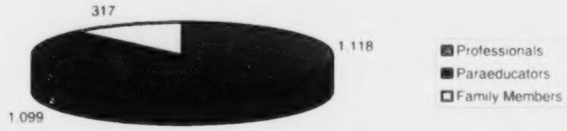
Grant Period: 1995 to 1999



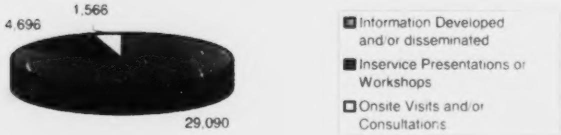
INFORMATION MATERIALS DEVELOPED AND/OR DISSEMINATED



INSERVICE PRESENTATIONS OR WORKSHOPS



STUDENT TEAM ASSISTANCE: ONSITE VISIT AND/OR CONSULTATION



TOTALS

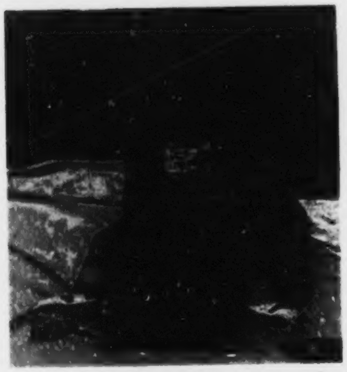
FACILITATION OF ON-SITE TECHNICAL ASSISTANCE USING A TRANDISCIPLINARY APPROACH

"Bi-monthly meetings were scheduled between (the Project), the child's legal guardians, and the entire educational team. This included the special education teacher, the teacher for the deaf, an occupational therapist, nurses, a physical therapist, a speech therapist and myself. In addition to advising us, you provided resources and individual instruction. As the child began to obtain skills, you guided the team towards the next stage of programming.

I am proud to say that within two years, the child progressed from having no functional communication skills to a receptive vocabulary of approximately 20 signs. As I transitioned her to a school age program, I was delighted to observe the development of her expressive use of language. The changes in this child's performance were remarkable at both school and home. In addition to communication skills, she was gaining cognitive skills, orientation and mobility skills and social and play skills.

The partnership developed between the team, the child's guardians and the Deafblind Project was essential to the successes this child obtained. I believe that everyone involved in this child's education and care obtained knowledge and skills that could transfer to another child." - from a teacher of the visually impaired/orientation and mobility therapist

"...This project has been very instrumental in facilitating a relationship between families and educators. These efforts have improved the effectiveness of services and supports for individuals in our district who are deafblind." - from an acting supervisor of special education



Facilitation of onsite technical assistance using a transdisciplinary approach

The Project collaborated with the Commonwealth's early intervention technical assistance organization to plan and deliver information and training to service providers and families of very young children who are deafblind. State-wide, regional, and local workshops were provided. On-site assistance was conducted, and was coordinated with local service providers. Frequent on-site visits to schools and homes provided technical assistance and training to child specific teams, classrooms and schools, agencies and families.

The Project continued to support a state and local interagency partnership model for transition teams of youth who are deafblind. With the support of two national projects (Technical Assistance Center from the Helen Keller National Center: HKNC-TAC, and Teaching Research Assistance to Children Experiencing Sensory Impairment: TRACES) a multilevel approach to improve the transition to adult life resulted in the intensive support of several young people who are deafblind, cross-training with colleagues, communication links with state level policy-making committees, and an increase in awareness and resources for the transition process.

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"It is hard to believe that 20 years have passed since our daughter, Janna, was first diagnosed with a degenerative disease of her central nervous system. At the time we thought only her sight was going to be affected, a difficult adjustment alone. But in a few short years her hearing followed by her ability to walk also was lost. In those first years when the adjustments are so difficult we felt so abandoned; a diagnosis was given and then we were sent home. No counsel, no direction, no hope.

I remember when we finally linked up with what is now the Pennsylvania Deafblind project I was so happy to find a support line and was thrilled to learn there were groups nation wide and meetings that I was invited to attend and learn. The very first one I went to had speakers and presentations on 'transition'. Transition needs seemed so very far away--I wanted help for my present circumstances and so tuned out much of what was being said. With hindsight I see that every experience and change involves a transition of some form or other and wish now I had paid closer attention.

Fortunately, our link to the Deafblind Project educated us on transition needs as the years rolled by and a transition 'team' was put together for Janna early in her high school years. The team met regularly and was a great instrument for making sure relevant issues were always in the forefront. Having a person from the Deafblind Project on the team was a plus. Often there would be differences of opinion and of focus between family, school and agencies but the representative from the Deafblind Project was able to act as a neutral party and direct a more effective blending of ideas"-from a parent.

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Pennsylvania State and Local Transition Team Partnerships

Highlights

Most valuable components of the process

- regularly scheduled meetings (nut and bolts) with an effective and timely action plan format
- longitudinal relationships among team members
- earlier transition planning
- guidance from the family and student
- networking with other local teams in state (use of videoconferencing in large state to make those connections)
- person-centered planning

Successes for PA students

- Attending college
- Living in home with peers
- Use of access technology skills gained
- Growth of supportive local community agencies
- Advocacy grant for deafblind
- Well-established teams who use the process well.

Challenges

Ongoing concerns and challenges

- Availability of adult services, especially for multihandicapped
- Early involvement from community agencies
- Keeping informal supports in place with distance issues (friendships near school & not near home, local gathering sites)
- Keeping parents involved at the level needed (may need to become assertive, become leaders)
- Dealing with mental health issues

Overall success

- Cohesive teams that have learned to listen to the consumer and involve them directly in the decision-making.
- Promotion of transition as necessary process that needs to happen rather than an event.

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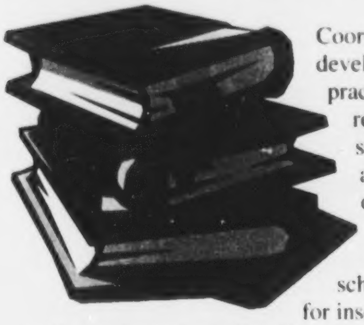
Challenges and Solutions



Coordination of staff development plans continues to be a challenge. Staff development must address changes in laws, regulations, and effective practices. For example, the 1997 reauthorization of IDEA was a topic requiring staff development. Out of IDEA have come changes in statewide assessment practices and in special considerations regarding assessment and educational programming for children who are deafblind. All of these changes require substantial time to plan and implement. Team members for a child who is deafblind may come from several different entities, and also may serve several different school districts or agencies. Frequently, there is a lack of coordination for inservice days among these team members, resulting in uneven or inefficient inservice schedules.

Also, there are specific teachers of the deaf or hard of hearing, and there are specific teachers for children with visual impairments. However, for children who are deafblind, there is not a stable cadre of teachers who serve children who are deafblind. Instead, children who are deafblind are educated in varied educational placements.

Itinerant teachers of children who are deaf/hard of hearing or visually impaired will continue to serve children who are deafblind. A solution is to ensure that these teachers assume more of a leadership role in assessing the child and developing the educational program. As children are included in their neighborhood schools, itinerant teachers are becoming more knowledgeable and skilled in supporting children who are deafblind. This also must be addressed at the preservice level with institutes of higher education. The Project initiated the use of student volunteers from special education, vision, and interpreter training programs at the 1999 Annual Family Learning Weekend, and had collaborated with various colleges and universities to provide continuing education and graduate credits.

Bruce is a teacher of the visually impaired in rural Pennsylvania. He attended an area workshop that was carefully planned in conjunction with the Local Interagency Coordinating Council for early intervention service providers. Project staff also accompanied him on a home visit to a young child's home. He appreciated the efforts of the Project in "piggybacking" on services and people in the region, and accompanying him on a home visit was a great service to him and his colleagues. - from an impact survey

An effective strategy has been to examine new and upcoming needs for staff development, develop a long-term plan for training, and present it to administrators. For example, reauthorization of IEA requires us to examine the need for braille through the assessment and IEP process, and literacy is a local and national concern. Therefore, we collaborated with other efforts to support effective practice for students with low incidence/sensory impairments. The result was a year long plan of quarterly institutes on literacy, with specific topics for sensory impairment, such as learning media assessment. The plan was presented to administrators, who were asked to make a commitment of staff time and resources. Teachers attended the quarterly institutes, developed action plans to implement newly learned skills, and shared the information with their administrators through evaluation of action plans. This partnership was very effective in ensuring that newly learned skills could be applied to children who are deafblind.

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The process for an effective transition to adult life brings many new experiences and challenges. While common to all teams, it is especially difficult to bring teams together when members come from different systems or organizations, such as adult service agencies and schools. Local resources may be limited due to a lack of exposure to the low incidence and heterogeneous nature of the deafblind population. A survey of families with children of transition age revealed that many were unfamiliar with the terminology and critical components of the transition process.

A consistent team process for conducting meetings, regularly scheduled meetings, self-evaluation of teams (e.g., "what are we learning"), a person centered planning approach, and a multilevel approach to evaluation of effectiveness all contributed to the success of the teams that supported young people in the transition process. We must educate families about the transition process, and begin very early to focus on the development of self-determination skills in children who are deafblind.

"...My son's educational team has gained incredible knowledge from the project as well. Various training seminars and educational resources have helped to keep the team fresh with ideas and motivated to continue teaching my son.." - from a parent

"...We often call upon the expertise of the Deafblind Project to further help parents. The Deafblind Project is certainly a valuable resource to families in Pennsylvania." - from a parent education coordinator of a parent training and information center

"I have seen firsthand the many benefits that your program has brought to families, county early intervention programs and providers in the Central Region. For one family in particular, your staff spent countless hours mobilizing resources from throughout the State to ensure that a child who is deaf and blind and his family received state-of-the-art community resources to address their needs. After services were in place for the family, your staff followed up with trainings for county case management staff and local providers." - from a regional early intervention coordinator

"All in all the Deafblind Project was the only way parents like ourselves could get the knowledge, support and contacts to raise a dual sensory impaired child."

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> "...I contacted the Deafblind Project to ask about effective teaching practices and to get any hints they could give me. The amount of information and support I have received has been absolutely wonderful! They lent me videotapes about deafblindness which I shared with our entire team as well as with the parents of these two students. The Deafblind Project also gave me tests which were specifically geared towards students with dual sensory impairments, as well as many very helpful and informative handouts. As the staff and I digested this information, we were able to call the Project with questions about what we were learning. A consultant has been to our preschool several times to answer questions about specific students as well as to present an inservice training to the staff."
> *- from a special education teacher*

Implications for Policy, Practice, and Research

Efforts to enhance state and local capacity to educate all students must also address children who are deafblind. Because the Commonwealth has made extensive strides in this direction, we have seen a benefit to children who are deafblind. We have made a good beginning, but intensive support is needed to ensure success. Training and technical assistance must be approached from at least these levels: child and family, classroom, school/school district or agency, local resources, and state level. Cross-training and co-training with other state and regional education consultants is necessary to promote awareness and information about children who are deafblind, and also ensure that Project personnel are knowledgeable about current practice. Partnerships with institutes of higher education will increase the skills and knowledge of future educators and service providers.

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Goal IV

To increase the utilization of effective and age-appropriate practices that will promote the integration of children with deafblindness with children with other disabilities and without disabilities

The focus of this goal was accomplished as children increased participation in school and community activities, and in membership in neighborhood schools.

"...The Project is dedicated to enhancing local capacity...Our elementary school has never included a child with deafblindness before. Thanks to the assistance given by (the project), our son is included full-time in his neighborhood kindergarten classroom. For the first time in five years, Alex is not being bussed an hour away from home." –from a parent

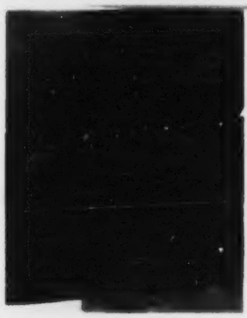
Information about resources and training opportunities related to this goal was included in the Commonwealth's Comprehensive System of Personnel Development Plan.

Support to families, educators, and service providers was provided in a variety of ways. Direct application of information was facilitated through mentoring in study groups, on-site and telephone consultation, and follow up from workshop activities. Workshops included case studies and action plan formats. Current effective practice was a foundation of training content. For example, a five-day summer institute was based on effective practices; these practices were generated from a national workshop for which a Project staff member attended as well as families from PA.

Partnering with team members allowed integration of services into the child's routines and environments. Person centered planning ensured that family and child priorities were addressed through the written educational plan. These practices assured the feasibility and implementation of recommendations.

State wide training in learning media assessment also included information on strategies to identify the optimal learning modes of children who are deafblind.

"Our son's transition into our local school system went extremely well, due to the expertise provided by the project." - from parents of a 16 year old son



Challenges and Solution

Children who are deafblind have complex educational needs. Schools and agencies may not have had prior experience in including these children.

Supporting team members through individualized technical assistance, and using a variety of training formats is necessary. Broadening technical assistance to meet school, school district, and agency needs provides benefits to many children, families, and personnel. Identifying local resources, and utilizing those resources during technical assistance activities also assists efforts to enhance local capacity.

"After services were in place for the family, your staff followed up with trainings for county case management staff and local providers." - from an early intervention services coordinator

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"The project has helped me to obtain information on the characteristics and teaching strategies and techniques to use with deafblind children." - from an early intervention teacher

"They have been instrumental in support of collaborative teaming and the necessary professional development to increase the skills of service providers." -from a vision support teacher

Implications for Policy, Practice, and Research

Local school districts and agencies must have access to expertise for including children who are deafblind. Stronger partnerships at a local level will result in joint investment for the success of inclusion.

Goal V

To evaluate the activities of the Project in order to increase accuracy of meeting needs of children who are deafblind and their families and to insure ongoing quality of service provision

This goal was achieved across activities in order to ensure that we maintained a connection with both current and future needs.

Team action plans served as ongoing monitoring instruments to review needs and technical assistance.

Review of data from the child count was conducted, as a reflection of technical assistance and information on early and accurate identification of children who are deafblind.

An increase in the number and participation of families in planning and delivering technical assistance was an integral component of the Project. We began with family volunteers who were available to talk with other families and to assist at workshops, and with family members as Advisory Council Members. Over the four years of the grant, we increased the number of family liaisons as well as their responsibilities (and contributions) to those served by the project.

> *"I am able to give parent to parent support, as well as facilitate study groups to address deafblind education."* - *from a family liaison*

After each major project activities, participants were telephoned by Project staff or family liaisons to inquire about the usefulness of the activity, and the potential need for further support. Technical assistance was provided as a result of the surveys, and the surveys functioned as a needs assessment to help in planning future activities.

> *"As a result of this training, I have changed my approach towards working with families. Instead of trying to "change" families, I am trying to incorporate what I do into their lifestyles."*

" I realized how important it is to start transition early. I thought of ways to relate transition to my curriculum. I thought of people I could use as resources. It empowered me to know what to do."

Advisory Council members, colleagues, and families reviewed Project materials, goals, and activities, helping to refine their usefulness and applicability. In the third year of the Project, Council members developed a comprehensive plan to ensure that desired outcomes occurred in the final year, and were also addressed in the next grant proposal.

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A federal site visit in 1996 commended the Project for its efforts in reaching goals. A review by the federal project officer of the 1998-1998 performance report indicated " excellent progress of the project for children with deafblindness."

> *"The very nature of the PA Deafblind Project is collaboration. Planning in response to service priorities, as well as more individualized technical assistance needs, occurs in a variety including collaboration with the family liaisons, and/or within and across related ISSP/IU supports. The close linkages of the project to the structure of the ISSP and its complement of technical assistance providers in the area of assistive technology, hearing impairment and visual impairment often lead to a team response to these requests."*

Challenges and Solutions

A considerable amount of time is required for data collection. Incorporating data collection into the timetable of activities, and listening to the perspectives of families, educators, and service providers yielded rich evaluative information. Data from the child count helped to drive Project activities. Utilizing family liaisons for telephone surveys on the impact of project activities provided us with an honest appraisal of efficacy, as well as information for a needs assessment process.

Implications for Policy, Practice, and Research

Multiple levels of evaluation are needed to evaluate project efficacy. Both formative and summative data must be collected to ensure maximum impact on children who are deafblind.

Recommendations for the United States Department of Education, Office of Special Education Programs

1. Support state efforts to provide a seamless system of service delivery for children who are deafblind

In order to maximize resources and to minimize disruptions in the lives of families and children, service delivery must have continuity. States with existing models of seamless service delivery could be in[illegible] address successful service delivery for children who are deafblind, and other states might approach this through state improvement grants or other opportunities.

2. Continue to place priorities on enhancing state and local capacity

Conducting this Project within the context of the Instructional Support System of Pennsylvania illustrated the many benefits of collaboration and partnerships, both at the state and local level.

3. Strengthen partnerships between deafblind projects, and institutes of higher education

Connections between deafblind projects and institutes of higher education can become even stronger through joint activities.

4. Increase support and funding to personnel preparation programs

We need more personnel with the skills to serve children who are deafblind. We must also embed this information in a variety of training programs (e.g., special education, speech-language pathology, physical therapy, counseling, school psychology, rehabilitation counseling)

5. Continue to emphasize family and consumer involvement

Families and consumers are vital in the planning and implementation of deafblind project activities. Improvement in the delivery of services for children who are deafblind can only occur with the active involvement of families and consumers.

6. Set priorities with a focus on self-determination, person centered planning, and increased participation in home, school and community activities for children who are deafblind

Effective practices must include these components across all age groups, with replicable examples and models.

7. Strengthen partnerships between deafblind projects and the national technical assistance consortium.

As the purpose of a national consortium includes enhancing state and national efforts, working papers and reports of replicable activities could be generated on a periodic (e.g., every six months) basis.

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PENNSYLVANIA DEAFBLIND PROJECT

FINAL GRANT REPORT

October 1995 – September 1999

APPENDICES

Supporting documents contained herein are representative samples of project outcomes.

Pennsylvania Deafblind Project

PENNTECH/Lancaster-Lebanon Intermediate Unit 13
6340 Flank Drive, Suite 600
Harrisburg, PA 17112

EC 307594

TABLE OF CONTENTS

- *Letters*
- *Advisory Council*
- *Sample Activities*
- *Products*

9-25-94

Dear Mary

I just wanted to tell you how great the Weekend - "A Celebration of Families" by the Deaf Blind Project was for Myself - Dane and the rest of my family!

I was especially please with how "at Home" and "part of the family" we were all made to feel.

The resources I have learned about will help Dane greatly and will - I believe - make him Happy and that is what it is all about.

Well thanks so much - for making me and Dane - and Patrick + Nicole + JoJo (my sitter) feel so very much a part of everything

Thanks - See ya Soon
(Next year in Lancaster)

Ruthann Dunleavy
+ Family

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Fran Warkomiski
Penn Tech
Flank Drive,Suite 600
Harrisburg,PA 17112

Nasrat Ghattas,MD,M.Div.
219 E.Willow Grove Ave.
B-3
Philadelphia,PA 19118

November 23,1994

Dear Ms Warkomski:

I am writing this letter to support your efforts and plans for the pennsylvania center of education for the deaf-blind. As a father of Nada Ghattas a six years old severely multply handicapped daughter,we had gained valiable support from the family weekends held in the last three years.Both me and wife enjoyed the seminars and brought important information home for future use.We also found meeting other families with deaf-blind children to be very helpful as we exchanged information and experiences.
We are looking forward to have more trainig and workshops to attend.The presence of qualified instructors is of course vital for conducting traning of bothof us as parents and our handicapped children.
We sincerely hope thatour staTE WOULD EXPAND ON THOSE PROGRAMS forthe help of children with special needs and their families.

Yours sincerely,

Nasrat Ghattas

610 Rembrandt Circle
Irwin, PA 15642
April 14, 1999

United States Department of Education
Office of Special Education

To Whom It May Concern:

I am happy to take this opportunity to express to you how The Pennsylvania Deafblind Project has supported our family over the past seven years. Our family includes two parents and three children. Our middle child, Alex, was born with deafblindness as a result of a rare syndrome. The living hasn't always been easy, but the PA Deafblind Project has certainly helped to make it manageable. I am listing just a few of the many ways the Project has impacted our lives:

1. Our family has been afforded many opportunities to attend trainings that have given us valuable educational and practical information to apply directly to our child with deafblindness, as well as share with his teachers on subjects ranging from communication, PATHs, MAPs, and IEP's, etc.

2. Through the Project's Learning Award, I was able to attend the National Deafblind Conference in Washington, D.C. where I witnessed first hand how successful and independent individuals with deafblindness can be.

3. At the Project's Annual Family Learning Retreat all of my children are given the opportunity to be involved with other families just like our own. My children without deafblindness realize that they are not alone and have made lasting friendships with other siblings just like themselves. The Family Learning Retreat also creates a forum for parents to share, learn and support each other. It is the highlight of the year for many families.

4. Most importantly, the Project has provided us technical support. The Project is dedicated to enhancing local capacity. Juli Baumgarner of The Project has been instrumental in assisting our family in including our son, Alex, in his local school district. Our Elementary school had never included a child with deafblindness before. Thanks to the assistance given by Ms. Baumgarner, our son is included full-time in his neighborhood kindergarten classroom. For the first time in five years, Alex is not being bussed an hour away from home.

United States Department of Education
Office of Special Education
April 14, 1999

In two capacities, I am able to give back to the Project, which I do with pleasure. I sit on the PA Deafblind Advisory Council whereby we assist the Project to focus on its mission and help accomplish its goals. Also, I am a Family Consultant. I am able to give parent to parent support, as well as facilitate study groups to address deafblind education.

My family has gained much through its affiliation with The Project. I ask that you support the proposal "Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth with Deafblindness." It certainly is appropriate that the name be changed – The Project has touched the hands of my husband and myself, giving us the power of information to touch our son and his teachers, thereby giving him the tools to one day reach out and touch the world in his own special way. Thank you for your consideration in funding this grant.

Very truly yours,

Molly Black

Molly Black
(Alex's Mom)

1712 Brown Ave
Bensalem 19020

April, 13 1999
RE: New Grant 10/99 thru 9/03

Dr. Fran James Warkomski
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Dr. Warkomski,

We are the parents of a 16-yr. old Deafblind child. In past years, through PA Deafblind Project, we have received priceless support for our son John and have greatly benefited from the parent-networking group. Our son's transition into our local school system went extremely well, do to the expertise provided by this project. With the help of Mary Frey's intervention, our local educators received an in-depth picture of our son's disabilities that neither my wife nor I could ever have accomplished. She included simulation for in servicing the staff and students, a wealth of other resource availability, as well as the support our family needed to make this mainstreaming situation as positive and successful as possible.

Another invaluable aspect of the project was our family reunion weekends. The seminars were not only extremely educational, but also created an opportunity for all the families to share each other's ideas and experiences. The social benefits of the weekends provided us with the realization that we are not alone in the world of the Deafblind.

As a past vice-president of the Deafblind Parents Association, we were able to continue with the continuity established on the weekends via monthly conferencing calls. We would discuss the most recent happenings, what's coming next or to plan for what's going on in our sector. Then we are able to distribute the information to other Deafblind people or their guardians in our district. All in all the Deafblind Project was the only way parents like ourselves could get the knowledge, support and contacts to raise a dual sensory impaired child.

Sincerely,

John and Ida Holcomb

Shari Jarrell
771 Whistle Stop Lane
Quakertown, PA 18951
(215) 536-7906

April 18, 1999

Central Instructional Support Center
Attn: Fran James-Warkomski
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

RE: Hand in Hand in Hand

Dear Fran:

I am writing to express my support of the PA Deafblind Project (Hand in Hand in Hand). My family has had tremendous support and resources available to us since our son was identified as being deafblind approximately 6.5 years ago. Without the resources offered by the PA Deafblind Project, my son would not be progressing as nicely as he is.

My son's educational team has gained incredible knowledge from the project as well. Various training seminars and educational resources have helped to keep the team fresh with ideas and motivated to continue teaching my son in a manner that is compatible for the entire team.

I have found that having a deafblind child is an extreme challenge in my life. However, the PA Deafblind Project has allowed for us to learn how to include him in our everyday activities. I look forward to continue having the expertise of the project's staff available to us in order to provide the support and resources needed for our special child.

Very truly yours,

Shari Jarrell

Shari Jarrell

AYJ

Andrea Y. Johnson
P.O. Box 5415 ~ Yeadon, PA 19050
Fax 610-623-8541 ~ Home Phone 610-623-8541 ~ Email techian1@prodigy.net

April 23, 1999

Pennsylvania Deafblind Project
6340 Flank Drive Suite 600
Harrisburg, PA 17112-2764

To Whom It May Concern,

My name is Andrea Johnson. I am the parent of Cejuana Johnson, "C.J.". She will celebrate her 11th birthday this August. Since the age of two she has been on the deafblind registry in Pennsylvania. The services offered by the Deafblind Project have been invaluable to C.J. and our family as well. Educating a deafblind child requires such unique techniques that without the Deafblind Project many would be in the dark. The project also help assist our family when after a number of surgeries my daughter was homebound and required homebound instruction. Juli and Mary gave me some direction when red tape tied up things. On a personla level the connections made at the family retreats for our family have been wonderful. To come together with other families living with similar circumstances is to say the least, heartwarming. The Deafblind Project is much needed to focus on this unique population of individuals.

Sincerely,

Andrea Y. Johnson

Andrea Y. Johnson

4/20/99 12:21 PM

From: Nelson Family
3850 Green Garden Road
Aliquippa, PA 15001

To Whom It May Concern:

We are writing in support of the Pennsylvania Deaf/Blind Project. Our daughter and family have received great support throughout these past years from the personnel and programs offered through the project. In the early years we were involved in family gatherings and conventions that linked us up with other families and educators who were dealing with similar issues of parenting and education. We received support in having a member of the project attend IEP's and transition meetings to give guidance and suggestions in meeting various program and training needs of our daughter. Members of the project have also been very helpful in procuring assistive devices needed for communication and education and for services needed for emotional and vocational support. The struggles would have been longer, harder, and less productive without the involvement of the Pennsylvania Deaf/Blind Project in our lives .

Sincerely,

Donna and Curtis Nelson

Mary Frey
Juli Baumgarner
Pennsylvania Deafblind Project
CISC
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Mary and Juli

It is spring and I am trying to catch up on all my mail after being away for a week! Usually during my week out-of-town, I take an evening to write some letters and notes to people that I have worked with throughout the year for various reasons. This year my social calendar was just as full as my work calendar, so no letters got done!

I have really enjoyed my work thus far with the Deafblind Project. I have met so many great people! And I have helped families find what they need on several occasions. I am doing something that I know makes a difference for people and it is very rewarding. I want to thank both of you for being one of those people that has made a difference for us in working with Daniel. I have learned so much in working with the Deafblind Project about things that I've never even heard of before Daniel came along. It is a very confusing path to follow when you have a child with so many challenges. There are too many decisions to make about too many services that are not always easy to understand. Of course in Daniel's case, even though medically he has been very involved, on a day to day basis the communication challenges have been the hardest to deal with. Not being able to talk to your child is heartbreaking to say the least. In working with the Project for the last two years, I have learned so much about ways to communicate and techniques to use in attaining communication.

I will never forget Daniel's first IEP that integrated the communication goals that I had for him. It was like trying to read a foreign language! I am so grateful that there is someone I can call for transcription and help with his IEP planning. As a member of the LICC, I have met several teachers and professionals that have told me how much they appreciate the support that the Project provides for them in the area of deafblindness. Dual sensory impairment is not the same as deaf or blind. It has very unique challenges as I have learned!

I look forward to working with you guys in the future. Daniel's transition to school with happen next year, and I know that with your help we will be able to write a plan that will work for him! Thank you.

Susan Shaffer
Shippensburg, PA

Mary, TA to Educators

Thank you so much for taking the time to come up for the visit. The tapes were marvelous. Myself, the aides, the parents, the O.T & Speech teacher viewed them. The O.T. was impressed. (yeah!) We are using a lot more of the cues for B to figure out what is happening. We have developed boxes with pom-poms, macaroni & different textures for him. We found that he can track objects or pictures in circles. He loves the Spin Art machine hooked up to his switch. The book "Every Move Counts" is pretty intense but the information/assessment seems to be something we can use.

We had A 's I.E.P. meeting yesterday & her parents definitely want her to go on to high school next year so were kind of down about that. I'm sure someone will be coming along to fill the space. Thanks again & we look forward to seeing you again.

L

Supporting information: Outcome 2

NOTE: Family and child surnames have been omitted intentionally out of concern for confidentiality.

From a phone interview conducted by a Family Consultant.

♥ *Doris is the foster mother of two children. One of the foster children is deafblind. Doris has had a hard time obtaining early intervention services in her rural, central Pennsylvania county. She states that she has been told: 'We are a small county, no funding, no discussion.'*

Doris claims that the Project has been her only salvation. The Project gave her the first information she could finally use regarding how and where to look for services. She states: 'The Project has been a godsend---it was the first chance to know what was available for (her daughter). The Project has been a lifesaver.'....

From a phone interview conducted by a Family Consultant.

♥ *Jean is the mother of Becky. Becky is four years old, a beautiful little girl full of wonder about the world. She was recently diagnosed as having Refsum's Syndrome. At the 1996 family learning retreat, Jean celebrated the fact that Becky said 'Mama' for the first time.*

Jean states that the family weekends provide her a way to meet other families in the same situation as her own. She appreciates the reliable child care available at the conferences. She has applied the themes of weekends to her own life. Last year's conference, 'Dreams,' already has helped her to realize some of the dreams for her daughter, Becky, by using the information learned.

From a phone interview conducted by a Family Consultant.

♥ *Donna's daughter is nineteen years old. She is being educated in a large urban public school, and is achieving age-level academic goals.*

Donna reported that the Project has most recently helped her family with transition goals, and has been very helpful to her family. It has helped her learn procedures and laws. It has been very helpful in learning about purchasing equipment and the services available. She has since applied that learning to her child's IEP. Because of the Project, she has an overall better handle on her family's situation. The best part of all is knowing that she is not alone.

Supporting information: Outcome 3

A teacher was interviewed regarding training and technical assistance.

- *Bruce Burr is a vision teacher located in rural northwestern Pennsylvania. Bruce attended an October 1996 workshop, and also received technical assistance through a home visit to a young child's home. The workshop was carefully planned in conjunction with the Local Interagency Coordinating Council for early intervention, and provided in that geographical area. Education consultants (and colleagues) from the Instructional Support System of Pennsylvania planned and provided the training, in collaboration with the Deafblind Project. A local teacher also assisted, demonstrating local resources.*

Bruce described four specific areas during a phone interview in which these activities were very beneficial:

- *A big factor mentioned was that the training was offered on a regional basis. It is difficult for professionals to break away an entire day to attend trainings which will include early and late travel. Because the training was provided locally, his agency was able to include several preschool teachers in the training. In this way, they could piggyback on the services and people providing those services. He would like to see more evaluation trainings provided in his region.*

- *Bruce noted that a great service to him was the ability to take the trainers to the child's home for diagnostic purposes. That was an incredible benefit to the staff.*

- *Bruce felt at an incredible disadvantage when he was told that the child was coming into the preschool program. The prior agency had not helped to plan for the transition to preschool. He felt that the education consultants from the training assisted the preschool staff with the basic information needed to get them started in working with this child. What the consultants taught complemented the preschool program and gave the teachers information and experience in dealing with children who have sensory impairments. The parents were given the opportunity to be involved also.*

- *And finally, he mentioned that it was a good refresher for him. He had not worked with a child at a preschool level for a long time.*

- *He said to keep doing what we are doing; he appreciates the efforts of the Project.*

Three families were interviewed by a Family Consultant regarding the technical assistance they had received from the project. The families were asked to relay what way, if any it had impacted their family.

- Technical assistance received was a Family Learning Award utilized to purchase computer software to assist the family in learning American Sign Language.

The child's mother stated the method of applying for the Family Learning Award was easy. She also appreciated the 'quick turn around time' in which she was notified. She stated she had let the ball drop at this point due to health concerns with her child. The family was notified there was some difficulty in finding a vendor for the particular software, but it had in fact been ordered. The family is 'eagerly awaiting ' their shipment.

- Technical assistance received was support at an Individual Education Plan team meeting.

The family had requested an Education Consultant and a Family Consultant to attend the first IEP team meeting for their child in a new school setting. The child was the first deafblind child this school had worked with. Information was shared concerning best practices for educating this student. Copies of the Hand in Hand curriculum were sent to both the family and the school staff.

The mother stated she was 'grateful for the support'. She had felt 'overwhelmed' at the prospect of attending this meeting on her own. She stated " It makes my case much easier when I have printed information for us all to refer to when there is a discussion.'

- Technical assistance received was support for the family regarding transition from early intervention to school age services.

The family expressed concerns because their school district 's LEA admitted they did not have a great deal of experience working with a deafblind child. Father expressed "People that have no idea what my daughter is all about will be deciding where she goes to school. ' Both the school district and the family have been provided with the resource material Assessing the School Age Student with Dual Sensory and Multiple Impairments. The family feels confident in their knowledge.

COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF PUBLIC WELFARE
OFFICE OF MENTAL RETARDATION
Central Region
Willow Oak Building, Room 430
P.O. Box 2675
Harrisburg, Pennsylvania 17105-2675

TELEPHONE NUMBER
(717) 772-6507
FAX: 772-6483

April 9, 1999

Dr. Fran James Warkomski, Ed.D., Director
Pennsylvania Deafblind Project
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, Pa. 17112-2764

Dear Dr. Warkomski:

I am writing to indicate my support for your proposal, "Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth with Deafblindness". As a Regional Early Intervention Coordinator for the Office of Mental Retardation, I have seen firsthand the many benefits that your program has brought to families, county early intervention programs and providers in the Central Region. For one family in particular, your staff spent countless hours mobilizing resources from throughout the State to insure that a child who is deaf and blind and his family received state-of–the-art community resources to address their needs.

After services were in place for the family, your staff followed up with trainings for county case management staff and local providers. I am hopeful that your program will receive the funds that it needs to continue its dedicated efforts on behalf of individuals who are deafblind and their families. If I can ever assist you in expanding your partnerships with State or local agencies, feel free to contact me.

Sincerely,

Jane C Courten

Jane E. Courten
Early Intervention Coordinator

THE OHIO STATE UNIVERSITY

Center for Special Needs Populations

Ackerman Place, Suite 440
700 Ackerman Road
Columbus, OH 43202-1559
Phone 614-447-0844
FAX 614-447-9043
www.csnp.ohio-state.edu

Nancy L. Zimpher
Dean

Larry A. Magliocca
Executive Director

April 27, 1999

Fran James Warkowski, Ed.D.
Director
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Fran:

I am writing this letter as Director of the Great Lakes Area Regional Resource Center to indicate enthusiastic support for your new proposal to serve children and families with Deafblindness. Your efforts over the years have been substantial and important to improvements of services to these children and their families. I hope very much that funding will continue to your group to support your ongoing work.

I have reviewed the proposed project activities of "Hand in Hand in Hand". It is an ambitious and worthy plan. I know we can continue our collaborative efforts from GLARRC to support your efforts. Please be assured that we will are willing and committed to working with you if you are funded.

Over the years your project has brought innovative and effective services. I believe your renewed emphasis on enhanced early identification, family involvement, and expanded partnerships is the way of the future.

Best of luck in your efforts in seeking a renewal to your efforts. If we at GLARRC may assist in any way, let us know.

We look forward to continuing our partnership in the future!

Sincerely,

Larry A. Magliocca, Ph.D.
Associate Professor and Director
GLARRC
The Ohio State University

B C I U 22

Dr. A. William Vantine
Executive Director

SPECIAL EDUCATION
FAX: 215-340-1639

BUCKS COUNTY SCHOOLS
INTERMEDIATE UNIT NO. 22
705 SHADY RETREAT ROAD
DOYLESTOWN, PA 18901

215-348-2940
TDD/TTY: 215-348-1127
FAX: 215-340-1964

April 20, 1999

Fran J. Warkomski, Ed.D.
Director
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Dr. Warkomski:

Please accept my letter of support for the Pennsylvania Hand in Hand in Hand Project. Families and school staff from the Bucks County, Pennsylvania area have been beneficiaries and participants in the project serving deafblind children for numerous years. Since the 1970's, it has been the philosophy in Bucks County to bring services to deafblind children in natural settings. For preschool children, our staff members have worked with infants and children in their homes building relationships with parents. For school-age children, our programs are based in public schools in order to enhance the relationship between special education and regular education.

Thanks to the volunteer efforts of staff, the Bucks County Intermediate Unit has exercised a leadership role in Eastern Pennsylvania. With support from Hand in Hand in Hand, we have been able to share our experiences with families and staff from a wide geographic area. I have personally seen the value of what can be achieved for children with deafblindness by learning from the successes and mistakes of others. I pledge the support of the Bucks County Intermediate Unit #22 for the project and urgently request continued funding from the Office of Special Education Programs.

Sincerely,

Richard O. Coe, Ed.D.
Assistant Executive Director
Special Education Services

ROC:hg

BCIU 22

Dr. A. William Vantine
Executive Director

BUCKS COUNTY SCHOOLS
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705 SHADY RETREAT ROAD
DOYLESTOWN, PA 18901

215-348-2940
215-757-0227
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April 16, 1999

Dr. Fran Warkomski
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Dr. Warkomski,

It is my pleasure to send this letter in support of the PA Deaf Blind Project, "Hand in Hand in Hand". I have been a Vision Support Teacher at Bucks County Intermediate Unit #22 for the past 25 years. I have known project coordinators, Mary Frey and Julie Baumgarner, for the past 10 years and have called upon their expertise on many occasions. They have always been willing to take serious counsel from teachers and make the necessary recommendations for the benefit of student needs. More importantly however, they have been instrumental in support of collaborative teaming and the necessary professional development to increase the skills of service providers.

The project coordinators also realize the vital importance of including parents as an integral part of the team. They design and coordinate family weekends that are informative and supportive for the families. It provides families the opportunity to learn more about home and school interventions, while allowing time for meeting others and sharing experiences.

I have more recently been involved with Mary Frey through a student's educational team. Mary has been very supportive and has helped us to establish a cohesive team with collaborative skills. Mary guides our meetings and helps to establish goals and successful implementations for our student. She comes to our team as a member but her leadership skills are well respected and appreciated. The resources and materials that are made available to the teams are informative with clear demonstrations of best practices.

In summary, I would like to emphasize the key role that the coordinators of the Deaf Blind Project play in the educational development of these children. They are a strong and vital part of the team. The resources that they provide are priceless in the scheme of the students' educational development. If you would like further information regarding the role of the Deaf Blind Project in its actual implementation, please do not hesitate to call me. I would be pleased to embellish further on the high regard I have for this most worthy State Project.

Sincerely,

Gail McQuown

Gail McQuown M.S.
Vision Support Teacher
Educational Technology Specialist

CEREBRAL PALSY ASSOCIATION OF DELAWARE COUNTY
LINDA JOY GROSS CENTER FOR
CHILD DEVELOPMENT
401 Rutgers Avenue, Swarthmore, PA 19081-2499
Phone (610) 543-8089 Fax (610) 328-1745

April 19, 1999

Fran James Warkomski, Ed.D.
Director
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Ms. Warkomski:

Two years ago two students with dual sensory impairments were placed in my preschool classroom. Although I had experience with both hearing impaired and vision impaired students, I had no experience with students with impairments of both senses. The challenges these students faced, especially in the area of communication, seemed overwhelming to me. I had no idea of how to deal with their very special needs.

I contacted the Pennsylvania Deaf-Blind Project to ask about effective teaching practices and to get any hints they could give me. The amount of information and support I have received has been absolutely wonderful! They lent me videotapes about deaf-blindness which I shared with our entire team as well as with the parents of these two students. The Deaf-Blind Project also gave me tests which were specifically geared towards students with dual sensory impairments, as well as many very helpful and informative handouts. As the staff and I digested this information, we were able to call The Project with questions about what we were learning. A consultant has been to our preschool several times to answer questions about specific students as well as to present an in-service training to the staff.

April 19, 1999
Page 2 of 2

The information and support we've received from the Pennsylvania Deaf-Blind Project has been invaluable. Our team has come very far in our knowledge and skills and we are doing a better job with this very special population. However, there is still much more for us to learn. It is very comforting to know that the talented staff at the Pennsylvania Deaf-Blind Project will be there to give us a hand as we grow and learn.

Sincerely,

Elaine Byrne

Elaine Byrne
Special Education Teacher

MONTGOMERY COUNTY INTERMEDIATE UNIT
SERVING THE SCHOOLS OF MONTGOMERY COUNTY

1605-B WEST MAIN ST. • NORRISTOWN PA 19403 • 610/539-8550 • FAX 610/539-7411

April 8, 1999

Ms. Mary Frey
Pennsylvania Deafblind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Dear Mary,

I am delighted to offer my support for your proposal, "Hand in Hand in Hand." During the school years 1996-97 and 1997-98 the Pennsylvania Deafblind Project provided invaluable support to myself and the entire educational team working with a preschool deafblind child enrolled at United Cerebral Palsy Association in Harleysville, PA. This on-going technical assistance and consultation helped us create a developmental, educational program to address the unique needs of this child.

Although I had been a teacher of blind and visually impaired children for over 25 years, I was not professionally prepared to serve a child with two sensory impairments. The teacher of deaf children, also felt unprepared to design a program for this child. We both sought the assistance of a professional who could bring both disciplines together. The Pennsylvania Deafblind Project filled this need beautifully.

Bi-monthly meetings were scheduled between yourself, the child's legal guardians, and the entire educational team. This included the special education teacher, the teacher for the deaf, an occupational therapist, nurses, a physical therapist, a speech therapist and myself. In addition to advising us, you provided resources and individual instruction. As the child began to obtain skills, you guided the team towards the next stage of programming.

I am proud to say that within two years, the child progressed from having no functional communication skills to a receptive vocabulary of approximately 20 signs. As I transitioned her to a school age program, I was delighted to observe the development of her expressive use of language. The changes in this child's performance was remarkable at both school and home. In addition to communication skills, she was gaining cognitive skills, orientation and mobility skills and social and play skills.

MCIU is an equal opportunity employment, educational, and service organization.

The partnership developed between the team, the child's guardians and the Deafblind project was essential to the successes this child obtained. I believe that everyone involved in this child's education and care obtained knowledge and skills that could transfer to another child.

It was a pleasure to work with you, as representative of the Pennsylvania Deafblind Project. I wish you future success in your endeavors. If I can be of further assistance, please do not hesitate to ask.

Sincerely.

Lynne Dellinger

Lynne Davis Dellinger
Vision Support Teacher
Orientation and Mobility Therapist

April 13,1999

Carol Haines
Capital Area IU 15
55 Miller Street, Box 489
Summerdale, PA 17093

To Whom It May Concern:

This letter is to share with you the importance of the Deafblind Project and it's impact on the ability for me to gain information about deaf/blind children. The project has helped me obtain information on characteristics and teaching strategies and techniques to use with deaf/blind children. I appreciated their willingness to be available to be consultants in my classroom. The consultant provided me with valuable information and kept me informed of inservices in this area.

This project is a very valuable assest to Special Education teachers of the deaf/blind.

Sincerely,

Carol Haines

Carol Haines
Early Intervention Specialist

HEMPFIELD AREA SCHOOL DISTRICT
ADMINISTRATION BUILDING • ROUTE 136 - WEST NEWTON ROAD • R.D.6, - BOX 76 - GREENSBURG, PA 15601 • (724) 834-2590

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DR. CHERYL S. TROGLIO
Asst. Superintendent

JOHN P. SCHUCK
Director of Business

SEAN GILLESPIE
Personnel Director

WAYNE JOHNSON
PR/Grant Writer

April 19, 1999

To Whom It May Concern:

This letter is written in support of the PA Deafblind Project "Hand in Hand in Hand." The current project has been very helpful in providing our school district with literature, technical assistance, and training to staff.

The efforts of this project has been very instrumental in facilitating a partnership between families and educators. These efforts have improved the effectiveness of services and supports for individuals in our district who are deafblind. Through these efforts the transitioning of a student from an approved private school into the public school setting has been very successful. Special accolades go to Julie Baughgardner who has been very instrumental in this transition process. She has been a very valuable consultant and a pleasure to work with.

As a district we look forward to being able to continue to work with the "Hand in Hand in Hand" project as it works to achieve its goals. We have been very fortunate to have this project available to serve our district needs. We support and recommend the continuation of this project.

If you have any further questions about our association with the Pennsylvania Deafblind Project or would like additional comments, please feel free to call 724-834-2590.

Sincerely,

Taundra K Krall

Taundra K. Krall
Acting Supervisor of
Special Education

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(412) 323-3950 • FAX (412) 323-3992

April 12, 1999

Fran James Warkomski, Ed. D.
Director
Central Instructional Support Center
6340 Flank Drive, Suite 600
Harrisburg, PA 17122-2764

Dear Dr. Warkomski,

This communication is a letter of support for the proposed Pennsylvania Deafblind Project, "Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth with Deafblindness." As an administrator of programs for students with exceptionalities in a district which has received strong support over the past ten years from this project, I endorse enthusiastically its continuance and the collaborative focus of its objectives.

Pittsburgh has been fortunate to have had the opportunity to educate a variety of students with deafblindness including two gifted deafblind students who graduated with honors from our secondary program. Continued technical assistance from your project enabled our school based team to augment the resources for these students and to offer additional training to team members and parents. Also, your project staff is to be commended by their efforts to attend every IEP/ transition meeting for these students. We are very proud that one of our former students is now serving on the advisory committee of the project.

We look forward to a continuing relationship with the project staff as our program continues to strive to bring enhanced services to deafblind students and their families.

Sincerely yours,

Kathryn M. Daugherty Ph D

Kathryn M. Daugherty, Ph. D.
Special Education Support Specialist
Programs for Students with Exceptionalities

cc: Dr. J. Kaye Cupples, Coordinator, Programs for Students with Exceptionalities

We are an equal rights and opportunity school district

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Dennis J. Huber, President
Richard L. Welsh, Ph.D., Vice-President

April 13, 1999

Nancy Lehr
CISC
6340 Flank Drive Suite 600
Harrisburg, PA 17112-2764

Dear Ms. Lehr:

Pittsburgh Vision Services is please to provide a letter of support in conjunction with your application for future funding to continue the valuable and essential efforts of the Pennsylvania Deaf Blind Project. Pittsburgh Vision Services has had a positive relationship with the project for over three years. This relationship has provided a close working relationship with Pittsburgh Vision Services' Deaf Blind Advisory Committee and most recently, the Deaf Blind Advocacy Committee. Your representation has provided these committees the opportunity to provide out reach services to teens that are deaf blind. These services have included members of the deaf blind advocacy committee being represented on transition teams to assist with future planning and the facilitation of the transition process from school to adult services. Also your project has assisted the committee with in-service training programs to human service agencies throughout the Pittsburgh area.

The Deaf Blind Advocacy Committee looks forward to the continued support of the Pennsylvania Deaf Blind Project. The specialized assistance that the project can provide the committee will assist with the committee's goal of establishing a teen support group in the Pittsburgh area.

The Deaf Blind Advocacy Committee feels a strong need in establishing support groups for teens that are vision and hearing impaired. Your project resources will be of great assistance in identifying prospective teens that may benefit from this group.

If I can provide any additional support with the submission of the proposal, please do not hesitate to contact me.

Sincerely,

Dennis W. Apter
Director, Vocational Services
Pittsburgh Vision Services

BEST COPY AVAILABLE

United Way

A Consolidation of the Greater Pittsburgh Guild for the Blind and Pittsburgh Blind Association

Dr. Fran Warkomski
Director
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Re: State and Multi-State Project for Children Who Are Deaf-Blind (84.326C)

Dear Dr. Warkomski:

This letter is to support the application your office is submitting for the 1999-2003 Deaf-Blind Center grant for Pennsylvania. The Center's work has been very helpful to teachers and other professionals serving individuals with deaf-blindness. I encourage the U.S. Department of Education to fund your application.

As a practicing teacher working with students with deafblindness, I have had numerous opportunities to interact with the Deafblind Project. The project has been extremely helpful as we have worked to develop appropriate programs for students.

Individuals with deaf-blindness are small in number, but the dual sensory loss creates needs that must be addressed by collaboration among service providers. I offer that support.

I am happy to endorse your proposal and provide the required commitment.

Sincerely,

Kristen Rapsher

Kristen Rapsher, M.Ed.

PENNSYLVANIA ADVISORY COUNCIL FOR CHILDREN WHO ARE DEAFBLIND

FOURTH ANNUAL MEETING
WEDNESDAY, SEPTEMBER 22, 1999
CENTRAL INSTRUCTIONAL SUPPORT CENTER, HARRISBURG

AGENDA

9:30 a.m.	Coffee and networking
10:00 a.m.	Introductions Review agenda
10:20 a.m.	Current status: ◆ 1995 - 1999 grant ◆ 1999 - 2003 grant ◆ 1999 - 2003 matchmaker grant
11:00 a.m.	Review Project PATH and update
12:15 p.m.	Lunch Networking
1:00 p.m.	Discuss current needs and concerns Discuss future plans, name change
2:00 p.m.	Action plan Kaizen Dates for next three meetings Joint events
3:00 p.m.	Adjourn

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September 22, 1999

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September 23, 1998

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Annual Meeting of Advisory Council
September 23, 1998

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Pennsylvania Advisory Council for Children Who Are Deafblind

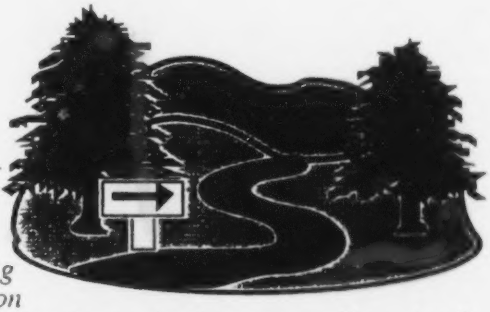
Third Annual Meeting
Wednesday, September 23, 1998
Central Instructional Support Center, Harrisburg

AGENDA

10:00 a.m. - 10:15 a.m.	Introductions and review agenda
10:15 a.m. - 10:45 a.m.	Review history maps
10:45 a.m. - 11:15 a.m.	A "PATH " for the Project
11:15 a.m. - 12:30 p.m.	Possibilities, probabilities, and dreams
12:30 p.m. - 1:15 p.m.	Lunch: Networking
1:15 p.m. - 2:00 p.m.	Focus work groups
2:00 p.m. - 3:00 p.m.	Action planning and Kaizen evaluation

PATH . . . . . *A process for*

PLANNING ALTERNATIVE TOMORROWS WITH HOPE



"PATH *is a way for a group of people, who share a common problem situation, to align ...• their purposes • their understanding of the situation • the possibilities for hopeful action • their actions for change, mutual support, personal and team development, and learning.*"

Jack Pearpoint, Marsha Forest, and John O'Brien, PATH Authors

GOAL: Describe Your Goal /Dream

What is your "vision" for your student or school? What key words, phrases, and images express these goals? Look ahead more than a year if this is a planning team that involves school and community.

FOCUS: "Future Focus" Prioritize!

Through the magic of time travel, you have opened your eyes to find that is _________ (one year from the current date). What does your school look like? What is going on? What important accomplishments have occurred? The goal(s) should be positive, possible, and revisited throughout!

NOW: What is the Current Situation?

The clock is now turned back to *"real" time.* It is ___________ (current date). You are now encouraged to feel and express the discrepancy between "what you want" and what "is." In this segment of time, share what is **NOW** going on with the student or members involved. What are some phrases and images to describe **"NOW"**?

ENROLL: Who Do You Need to Enroll?

You now have a space that represents the "path" between where you want to be and where you are now. In addition to a lot of hard work, ***who do you need to get involved (i.e. enroll)*** in order to help you reach your goals? Be specific -- identify names, positions of school or community members. Think about people who have resources, can influence attitudes, etc.

STRONGER: Strengthening Activities

In addition to people, there are "other things" -- strengths such as ***knowledge, skills and actions*** that you personally as well as your school or community as an organizational team can do or provide. How can you maximize your efforts to achieve your goals?

FIRST STEP: Immediate Actions

At this point in the process, identify the ***immediate "next steps"*** that must be taken. Prioritize and set realistic limits.

NEXT MEETING: Set Your Next Meeting Date

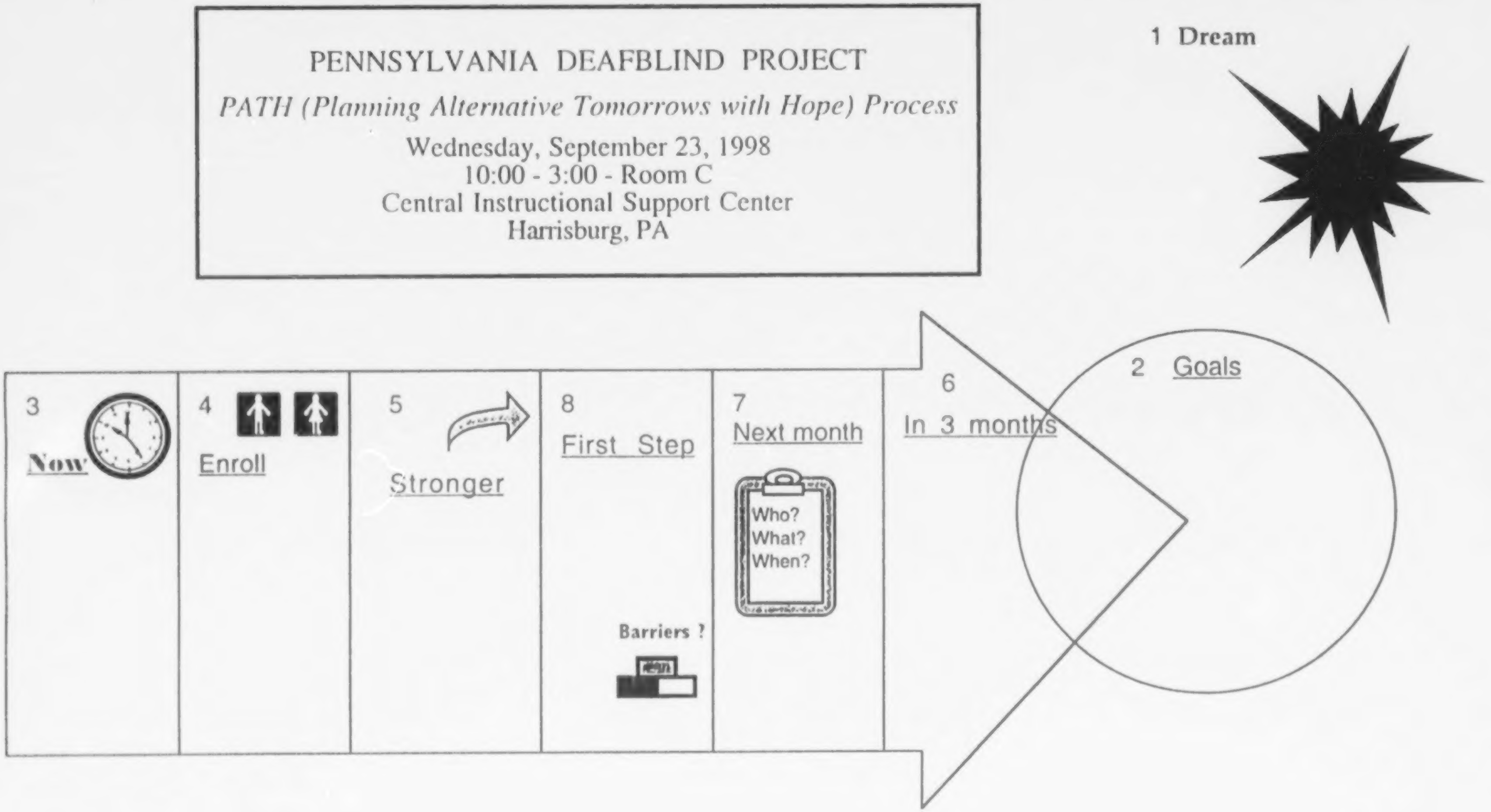
Be specific (think about the **"who"**, **"what"** and **"when"**). Also, list any concerns and develop strategies to meet them. Action plan!

Adapted from: J. Pearpoint, M. Forest, J. O'Brien. A Workbook for PATH. Toronto, Ont: Inclusion Press

PENNSYLVANIA DEAFBLIND PROJECT

PATH (Planning Alternative Tomorrows with Hope) Process

Wednesday, September 23, 1998
10:00 - 3:00 - Room C
Central Instructional Support Center
Harrisburg, PA



1 Dream

2 Goals

3 Now

4 Enroll

5 Stronger

8 First Step

Barriers ?

7 Next month

Who?
What?
When?

6 In 3 months

Adapted from **Planning Alternative Tomrrows With Hope (PATH)**
Jack Pearpoint, Marsha Forest and John O'Brien, Toronto, Ont: Inclusion Press

AGENDA

ADVISORY COUNCIL

Tuesday, September 23, 1997

* * * * * *

10:00 - 10:15	Introductions Review Agenda
10:15 - 10:30	Mission, Roles
10:30 - 11:15	"You & Me" video Examples of TA
11:15 - 11:30	Census Report (draft)
11:30 - 12:00	General Information regarding I.D.E.A. changes
Noon	Lunch
12:45 - 1:00	Review Action Plan - June 4
1:00 - 2:30	Generate Future Directions Dissemination Resources –Materials
2:30 - 3:00	Specific Topics/Concerns Wrap-up Action Plan Plan Phone Calls Kaizen

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September 23, 1997

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September 23, 1997

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PA Advisory Council for Children Who Are Deaf-Blind

First Annual Meeting
September 24, 1996
PennTech, Harrisburg

Agenda

10:00 am - 10:15 am	Review agenda and notebooks
10:15 am - 11:00 am	Introductions and roles
11:00 am - noon	Review mission of the Project
	Review activities and outcomes of the Project
Noon - 12:30 pm	Discuss mission and outcomes of the Advisory Council
12:30 pm - 1:30 pm	Lunch - guest Dr. William Penn
1:30 pm - 1:45 pm	Begin to develop mission and specific outcomes
1:45 pm - 2:30 pm	Formalize the mission and outcomes
2:30 pm - 3:00 pm	Action Planning - ways to communicate with dates - 1997 annual meeting date
	Kaizen

MRF/9-96/Adv. Coun.

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PA DEAF-BLIND PROJECT
September 24, 1996

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PA DEAF-BLIND PROJECT
September 24, 1996

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TOGETHER WE'RE BETTER:LEARNING THROUGH PLAY & HUMOR

PENNSYLVANIA DEAFBLIND PROJECT: FAMILY LEARNING WEEKEND

June 25, 26, 27, 1999 - Holiday Inn @ Grantville
PARENTS' AGENDA

FRIDAY, 6/25	ROOM	ACTIVITY
3:00 - 8:00 p.m.	Royale Foyer	Registration
6:00 - 8:30 p.m.	Congressional	Hospitality: meet families & staff; do fun activities
7:00 - 9:00 p.m.	Indoor Pool	Swim Party

SATURDAY, 6/26	ROOM	ACTIVITY
7:15 - 8:30 a.m.	Saloon	Buffet breakfast
8:30 a.m.	Royale II	New Families drop off children for child care
8:45 a.m.	Royale II	Rest of families drop off children for child care
8:30 - noon	See child schedule	Child care & activities provided
9:00 - 9:45 a.m.	Royale III	Welcome, Orientation, Project Review, Introductions
9:45 - 10:30 a.m.	Royale III	Session: Bob Naseef, Presenter
10:30 - 11:00 a.m.	Royale III	Coffee break discussion groups
11:00 a.m. - noon	Royale III	Session: Bob Naseef, Presenter
Noon	See child schedule	Promptly pick up children from activities
Noon - 1:30 p.m.	Saloon	Buffet lunch
1:30 p.m.	Royale II	Families drop off children for child care
1:30 - 4:30 p.m.	See child schedule	Child care & activities provided
1:45 - 2:15 p.m.	Royale III	Parent sharing - Shaffer, Gerlach, Williams
2:15 - 3:00 p.m.	Royale III	Session: Bob Naseef, Presenter
3:00 - 3:30 p.m.	Royale III	Coffee break discussion groups
3:30 - 4:30 p.m.	Royale III	Session: Bob Naseef, Presenter
4:30 p.m.	See child schedule	Promptly pick up children from activities

SATURDAY, 6/26	ROOM	ACTIVITY
5:30 - 6:15 p.m.	Royale III	Children's dinner; Parents' snacks
6:30 - 7:30 p.m.	Royale II	Family activity
7:30 p.m.	Royale III	Ice cream social
8:00 p.m.	Royale II	Drop children off at activities
8:00 - 11:00 p.m.	See child schedule	Child care & activities provided OR in-room child care (if signed up)
8:00 - 11:00 p.m.		Parents' night out for dinner
8:00 - 11:00 p.m.	Royale III	Hospitality Room
8:00 - 11:00 p.m.	Senate Suite	Pre-teens Pizza Party
8:00 - 11:00 p.m.	Presidential Suite	Teens Pizza Party
11:00 p.m.	See child schedule	Promptly pick up children from activities

SUNDAY, 6/27	ROOM	ACTIVITY
7:30 - 8:45 a.m.		Breakfast
8:45 a.m.	Royale II	Drop off children for activities
8:45 a.m. - 12:30 p.m.	See child schedule	Child care & activities provided
9:00 - 9:30a.m.	Royale III	Parent sharing about Hand in Hand Study Group -Weaver, Hilderbrand, Farnsworth, Black
9:30 - 10:30 a.m.	Royale III	Session: Bob Naseef, Presenter
10:30 - 11:15 a.m.	Royale III	Feedback on sibling sessions: Emily and Sheri
11:15 - Noon	Royale III	Evaluation and wrap-up: Mary, Jeanne, Kathy
Noon - 12:30 p.m.	Front Desk	Check out of hotel
12:30 p.m.	See child schedule	Promptly pick up children from activities
Noon - 1:00 p.m.	Outside of Royale III	Pick up box lunches

WELCOME

TO

FAMILY LEARNING RETREAT

ADULT SCHEDULE

FRIDAY, JUNE 26, 1998

TIME	ACTIVITY	ROOM
3:00 p.m. to 9:00 p.m.	Registration	ROYALE FOYER
6:30 p.m.to 9:30 p.m	Hospitality	CONGRESSIONAL
7:00 p.m. to 9:00 p.m.	Swim Party	INDOOR POOL

SATURDAY, JUNE 27, 1998

TIME	ACTIVITY	ROOM
7:00 a.m.to 9:30 a.m.	Registration	ROYALE FOYER
7:15 a.m. to 8:30 a.m.	Buffet Breakfast 7:45 a.m. Announcements	SALOON
8:00 a.m. to 12:15 p.m.	Childcare Activities	Meet in GRANDE III
8:15 a.m. - 8:30 a.m.	First-time Family Orientation	CONGRESSIONAL
8:35 a.m. to 9:20 a.m.	Welcome to all, Opening Session	ROYAL I AND II
9:30 a.m. to 10:30 a.m.	CONCURRENT SESSIONS	
	Blue: Meaningful Education Plans - Pot of Gold	ROYAL I
	Red: Diversity of Social Skills and Behavior	ROYAL II
10:30 a.m. to 11:00 a.m	Coffee Break Discussion Groups	CONGRESSIONAL
11:00 a.m. to noon	CONCURRENT SESSIONS	
	Blue: Meaningful Education Plans - Pot of Gold	ROYAL I
	Purple: Put on Your Ruby Slippers - O & M	ROYAL II
Noon to 1:30 p.m.	Buffet Lunch	SALOON
1:30 p.m. - 4:45 p.m.	Childcare Activities	GRANDE III
1:45 p.m. - 2:00 p.m.	Parents share about "Hand in Hand" Study Group	ROYAL II
2:00 p.m. - 3:00 p.m.	CONCURRENT SESSIONS	
	Yellow 1: Building a Rainbow: Early Communication	ROYAL I
	Green 1: Experiencing a Rainbow of Technology	ROYAL III
3:00 p.m. - 3:30 p.m.	Soda Break Discussion Groups	CONGRESSIONAL
3:30 p.m. - 4:30 p.m.	CONCURRENT SESSIONS	
	Yellow 2: Building a Rainbow of Communication	ROYAL I
	Green 2: Experiencing a Rainbow of Technology	ROYAL III
4:30 p.m. - 5:00 p.m.	Free Time	
5:00 - 6:30 p.m.	Buffet Dinner with Sundae Bar 6:00 p.m. - Announcements	GRANDE I & II

Saturday continued next page

SATURDAY NIGHT FAMILY ACTIVITIES

TIME	ACTIVITY CHOICES	ROOM
7:00 p.m. - 9:30 p.m.	Meet and talk with Mentors	ROYAL I
	Hi-Tech Activities	ROYAL III
	Assistive Technology Activities	REGENCY
	Pizza Party - Teens	GOVERNORS
8:00 p.m. - 10:30 p.m.	Childcare Activities (if signed up previously)	GRANDE III
8:00 - midnight	Hospitality for Parents and Staff	CONGRESSIONAL

SUNDAY, JUNE 28, 1998

TIME	ACTIVITY	ROOM
7:15 a.m. - 8:30 a.m.	Buffet Breakfast 7:45 a.m. - Announcements	SALOON
8:15 a.m. - 11:15 a.m.	Childcare Activities	ROYALE II
8:45 a.m. - 10:30 a.m.	Somewhere Over the Rainbow, Way Up High	CONGRESSIONAL
10:30 a.m. - 11: 00 a.m.	Kaleidoscope: Together With Brothers and Sisters	CONGRESSIONAL
11:00 a.m. - 12:30 p.m.	Box Lunches Available	CONGRESS. FOYER
11:00 a.m. - 1:15 p.m.	Childcare (if signed up previously)	ROYALE II
11:00 a.m. - 1:00 p.m.	PA Parents for Deaf-Blind Group Meeting	CONGRESSIONAL
By Noon	Check-Out	
1:30 p.m.	Late Check-Out (if signed up previously)	

HAVE A SAFE JOURNEY HOME.

WE HOPE TO SEE YOU AGAIN NEXT YEAR.
June 25, 26, 27, 1999
Same Place!

Welcome to the Pennsylvania Deafblind Project's Family Learning Retreat !

"Making Connections: Hand in Hand in Hand"

Hope you had a safe journey here to the heartland of the keystone state. We have a busy weekend of activities and sessions planned. Time is also set aside for getting to know one another, sharing meals, telling stories, enjoying our hospitality.

During Saturday's activities, the children will be working on scenery and puppets for a show later that day as directed by two artists from the State College area. They will be making percussion instruments for the Saturday evening family activity.

The adults will be mapping family interests, identifying community resources, brainstorming ways to be involved in local activities, learning strategies about how to connect information between home and school, deciding on the first steps to "make connections: hand in hand in hand".

We are pleased to have staff from Overbrook School for the Blind as our child care workers and staff from the Instructional Support Centers to assist us this weekend. Thank you.

If we can be of any help or answer any questions throughout the weekend, please come and ask us.

Mary, Juli - Education Consultants
Nancy - Support Staff
Ellen, Molly, Stacy - Family Consultants

Friday Schedule - April 11, 1996

Time	Activity	Room
3:00 - 9:00 p.m.	Registration	Atrium
7:00 - 10:00 p.m.	Hospitality - activities and snacks	Alumni Lounge
(8:30 p.m.)	(Child care workers meeting)	(Colonial II)

ADULT SCHEDULE

Saturday, April 12, 1997

Time/Room	Board Room	Writing Room	Colonial I	Colonial II	PennState	Alumni Lounge
7:15 - 8:30 a.m.	Buffet Breakfast					
8:45 - 9:15 a.m.		New Family Orientation				
9:15 - 9:30 a.m.			Welcome - Fran			
9:30 - 10:00 a.m.			Hand in Hand in Hand	Mary & Juli		
10:15 -11:00 a.m.			Making Connections	Janet, Mary, Juli, Molly, Ellen, Stacy		
11:00 a.m. - noon			Group 1 - Juli, Tom, Kay	Group 2 - Janet, Susan, Judy	Group 3 - Mary, Mark	
12:15 - 1:30 p.m.	Buffet Lunch					
2:00 - 3:15 p.m.			Group 1 - Juli, Tom, Kay	Group 2 - Janet, Susan, Judy	Group 3 - Mary, Mark	
3:30 - 4:45 p.m.						Parent Group Meeting (optional)

PA Deafblind Project

FAMILY SCHEDULE

Family Learning Retreat

Saturday evening, April 12, 1997

Time/Room	Ballroom D	Ballroom C	Ballroom E	Alumni Lounge	Ballroom A	Ballroom B	Mt. Nittany
4:45 - 5:00 p.m.	Puppet Show						
5:30 - 6:45 p.m.		Buffet Dinner					
7:00 - 7:45 p.m.			Family Activity (in D & E)				
7:30 - 8:30 p.m.		Ice Cream Sundae Bar					
8:00 - 10:00 p.m.	Child Care (video room)		Child Care	Adults - Hospitality	Child Care	Child Care	Child Care - infants & toddlers

Please pick up your children from childcare by 10:00 p.m. !

Enjoy a good night's rest !

unday, April 13, 1997

oom	Colonial I & II
akfast	
	Helping Hands - Juli, Jane, Linda
	Action Planning Group 1 - Juli, Tom, Kay Group 2 - Janet, Susan Group 3 - Mary, Mark
	Final Connections Mary, Juli, Mark, Susan, Tom, Janet, Kay, Fran
h - eat in	

ur hotel room and pay for any incidental costs.
ave a safe trip home!

CHILD CARE AND ACTIVITIES SCHEDULE

Saturday, April 12, 1997

8:30 a.m. / 1:45 p.m. NEW families drop off children for care and activities. Please pick up children by 12:00 noon / 5:00 p.m.

8:45 a.m. / 1:45 p.m. "VETERAN" families drop off children for care and activities. Please pick up children by 12:00 noon / 5:00 p.m.

	Gilpin Room	Ballroom A	Ballroom B	Ballroom C	Ballroom D	Ballroom E	Mt. Nittany Room
7:15 a.m. to 8:30 a.m.	BUFFET BREAKFAST -- BOARDROOM						
9:00 a.m. to 9:30 a.m.				"Opening" All children Wilkerson			
9:40 a.m to 10:45 a.m.	Staff Room or "Quiet" Room	Siblings Stewart & Critchlow	Child Care	Teens Wilkerson	Child Care	Child Care	Child Care
10:50 a.m. to 11:20 a.m.		Siblings Stewart & Critchlow		3-yr-olds Wilkerson			
11:30 a.m. to 12:00 noon				4-yr-olds Wilkerson			
12:15 p.m to 1:30 p.m.	BUFFET LUNCH -- BOARDROOM						
1:45 p.m. to 3:00 p.m.	Staff Room or "Quiet" Room	Siblings Stewart & Critchlow	Child Care	5, 6, 7 yr olds Wilkerson	Child Care	Child Care	Child Care
3:15 p.m. to 4:30 p.m.		Siblings Stewart & Critchlow		8, 9, 10, 11 yr olds Wilkerson			

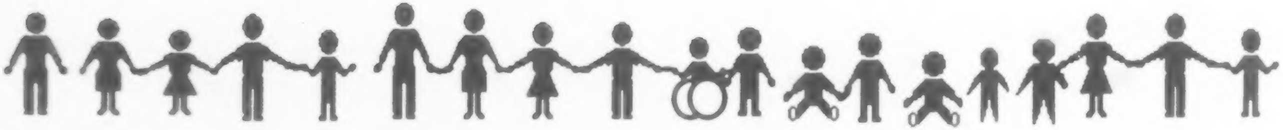
Possible afternoon trip to museum for teens.

CHILD CARE AND ACTIVITIES SCHEDULE

Sunday, April 13, 1997

8:45 a.m.: Drop off children for child care and activities. Pick up at 12:00 noon.

	Boardroom	**Mt. Nittany Room**	**Ballroom B**	**Ballroom C**	**Ballroom D**	**Ballroom E**
7:15 p.m. to 8:30 p.m.	Buffet Breakfast					
8:45 p.m. to 12:00 noon		Child Care	Child Care	Child Care	Child Care	Child Care
12:00 noon	Boxed Lunch					



PENNSYLVANIA DEAF-BLIND PROJECT

AGENDA
DREAMCATCHERS
A Family Learning Retreat Weekend

Friday, May 31, 1996

3:00 p.m. - 7:30 p.m.	Registration -- Hotel Lobby (2nd floor)
6:30 p.m. - 10:00 p.m.	Hospitality -- Harrisburger Room (3rd floor)
7:30 p.m. - 9:00 p.m.	Child care meeting for Overbrook staff in United States Board Room (3rd floor)

Speakers and Facilitators

PA Deaf-Blind Project:
- Juli Baumgarner
- Molly Black
- Cynthia Jackson-Glenn
- Mary Frey
- Ellen Blackburn
- Nancy Lehr
- Stacy Gerlach

Overbrook School for Blind: Dael Cohen, Ray Bailey

PennTech:
- Tom Clouse
- Lynn Dell
- Susan Lindsey
- Rick Creech
- Irene Hughes
- Mark Steciw
- Janet Sloand-Armstrong
- Anita Iurlano
- Fran Warkomski

University of Louisville: Sheri Moore

Parent Education Network: Deb Rauscher

PA Parents for Deaf-Blind: Ralph Warner

Staff from Overbrook School for the Blind -- Child Care

- Dael Cohen (Coordinator)
- Ray Bailey
- Marguerite Bradley
- Yvette Clover
- Sue DeAngelis
- Cathy Domizio
- Sheila Downing
- Kendall Edwards
- Monica Edwards
- Emma Fala
- Fran Fanelli
- Clarice Hicks
- Roxanne Scott
- Jill Sobota
- John Thomas
- Donna Williams

Artists

Barbara Gregson - mime and movement
Janice Henry - storytelling
Lauri and Tom Reese - music

Saturday, June 1, 1996

7:15 a.m. - 8:30 a.m.	Breakfast Buffet -- Ballrooms A and B (2nd floor)			
8:30 a.m. - 9:00 a.m.	Drop off children for child care and activities (separate schedule). Pick up at 11:45 a.m.			
9:00 a.m. - 9:15 a.m.	Welcome - Fran Warkomski		Carlisle Room (2nd floor)	
9:15 a.m. - 10:00 a.m.	Orientation Meeting - Mary Frey and Juli Baumgarner		Carlisle Room (2nd floor)	
10:00 a.m. - 10:15 a.m.	BREAK (coffee and tea)			
	Carlisle Room 2nd floor	**Leland Board Room 2nd floor**	**Penn Harris Room 3rd floor**	**Harrisburger Room 3rd floor**
10:15 a.m. -	"Dreams and Future Plans" *Janet Armstrong*	BREAKOUT SESSIONS AS FOLLOWS:		
- 11:45 a.m.		Parents of Young Children *Janet Armstrong, Mark Steciw*	Parents of School-age Children *Juli Baumgarner, Anita Iurlano*	Parents of Young Adults *Dael Cohen, Ray Bailey, Cynthia Jackson-Glenn*
12:00 noon - 1:15 p.m.	.Lunch Buffet -- Ballrooms A and B (2nd floor)			
1:45 p.m.	Drop off children for child care and activities (pick up at 4:30)			
2:00 p.m. - 3:00 p.m.	"Nuts and Bolts Parent Tips for Caring and Sharing" *PennTech Staff*	BREAK		
3:00 p.m. -	"Communication Styles" *Deb Rauscher*	BREAKOUT SESSIONS AS FOLLOWS:		
- 4:30 p.m.		Parents from Eastern PA *Lynn Dell, Stacy Gerlach*	Parents from Central PA *Tom Clouse* *Ellen Blackburn,*	Parents from Western PA *Anita Iurlano, Molly Black*

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Saturday (continued)		
5:00 p.m. - 6:30 p.m.	Sit-down Dinner -- Ballrooms A and B (2nd floor)	
6:30 p.m. - 8:15 p.m.	Family Activity -- Carlisle Room (2nd floor) Barbara Gregson, Lauri and Tom Reese -- mime, movement, improvisation, music, dreams	
8:15 p.m. - 10:15 p.m.	Child care and activities available	
8:15 p.m - 10:15 p.m.	Parents Time -- Carlisle Room (2nd floor)	*Please be prompt. Pick up children by 10:15*

Sunday, June 2		*Remember to check out by 1:00 p.m. or request late check-out at hotel front desk..*
7:15 a.m. - 8:30 a.m.	Breakfast Buffet -- Ballrooms A and B (2nd floor)	
8:30 a.m.	Drop off children at child care and activities (pick up at 11:30)	
9:00 a.m. - 9:30 a.m.	Summary of Sibling Group Discussions Sheri Moore	Carlisle Room (2nd floor)
9:30 a.m. - 10:00 a.m.	Parent Group Ralph Warner	Carlisle Room (2nd floor)
10:00 a.m. - 11:30 a.m.	"Most Effective Practices -- Reaching Your Dream" Juli Baumgarner and Mary Frey	Carlisle Room (2nd floor) (coffee and tea)
11:45 a.m. - 1:00 p.m.	Box Lunch -- Ballrooms A & B (2nd floor)	
1:00 p.m. - 3:00 p.m.	*OPTIONAL: Meeting of PA Parents for Deaf-Blind*	*Penn Harris Room (3rd floor)*

PA DEAF-BLIND PROJECT
"DREAMCATCHERS"
CHILD CARE AND ACTIVITIES SCHEDULE

Saturday, June 1, 1996

8:30 a.m. - 9:00 a.m.	Drop off children for care and activities as per schedule. Pick up at noon.					
	Lebanon/York Ballroom (2nd floor)	**Bridgeport Boardroom (2nd fl)**	**New Governor Boardroom (2nd fl)**	**Lochiel Boardroom (3rd fl)**	**United States Boardroom (3rd fl)**	**William Penn Boardroom (3rd fl)**
9:00 a.m. - 10:00 a.m.	Childcare and activities OSB staff	Child care and quiet room OSB staff	OSB staff	Puppet-making OSB staff	Dreamcatchers w/siblings ☆ - Sheri Moore	Storytelling Janice Henry
10:00 a.m. - 10:15 a.m.	B	R	E	A	K	
10:15 a.m. - 11:00 a.m.	Childcare and activities OSB staff	Child care and quiet room OSB staff	Mask-making Barbara Gregson	Puppet-making OSB staff	Dreamcatchers w/siblings Sheri Moore	Storytelling Janice Henry
11:00 a.m. - 11:45	Childcare and activities OSB staff	Child care and quiet room OSB staff	Mask-making Barbara Gregson	Puppet-making OSB staff	Dreamcatchers w/siblings Sheri Moore	Storytelling Janice Henry
12:00 noon - 1:45 p.m.	L	U	N	C	H	
1:45 p.m. - 2:00 p.m.	Drop off children for care and activities as scheduled. Pick up at 4:30 p.m.					
2:00 p.m. - 2:45 p.m.	Movement & Improvisation Barbara Gregson	Child care and quiet room OSB staff	Childcare and activities OSB staff	Puppet-making OSB staff	Dreamcatchers w/siblings Sheri Moore	OSB staff
2:45 p.m. - 3:00 p.m.	B	R	E	A	K	
3:00 p.m. - 3:45 p.m.	Practice for Performance 𝄞 ♪ Barbara Gregson	Child care and quiet room OSB staff	Childcare and activities OSB Staff	Puppet-making OSB staff	Dreamcatchers w/siblings Sheri Moore	Face painting Irene Hughes ☺
3:45 - p.m. - 4:30 p.m.		Child care and quiet room OSB staff	Childcare and activities OSB Staff	Puppet-making OSB staff	Dreamcatchers w/siblings Sheri Moore	Face painting Irene Hughes
🍴 5:00 p.m.	D	I	N	N	E	R

Saturday, June 1, 1996 (con't)

8:15 p.m.	Child Care and Activities Available (Pick up by 10:15 p.m.)					
	Lebanon/York Ballroom (2nd floor)	**Bridgeport Boardroom (2nd floor)**	**New Governor Boardroom 2nd floor**	**Lochiel Boardroom (3rd floor)**	**United States Boardroom (3rd floor)**	**William Penn Boardroom (3rd floor)**
8:15 p.m. - 9:15 p.m.	Child care and activities	Quiet room	VCR Movies		VCR Movies	Music (teens) ♪ Lauri & Tom Reese
9:15 p.m. - 10:15 p.m.	OSB Staff	OSB Staff	OSB Staff	OSB Staff	OSB Staff	OSB Staff

Get a REALLY good night's sleep!!

Sunday, June 2, 1996

8:30a.m.	Drop off children for care and activities as scheduled. Pick up at 11:30 a.m.					
	Lebanon/York Ballroom (2nd fl)	**Bridgeport Boardroom (2nd fl)**	**New Governor Boardroom (2nd fl)**	**Lochiel Boardroom (2nd fl)**	**United States Boardroom (2nd fl)**	**William Penn Boardroom (3rd fl)**
8:45 a.m. - 9:30 a.m.	Child care and activities OSB Staff	Quiet room OSB Staff	Masks OSB Staff	Puppets OSB Staff	Dreamcatchers (finish up) OSB Staff	Music Lauri and Tom Reese
9:30 a.m. - 9:45 a.m.	B	R	E	A	K	
9:45 a.m. - 10:45 a.m.	Child care and activities OSB Staff	Quiet room OSB Staff	Masks (finish up) OSB Staff	Puppets (finish up) OSB Staff	Dreamcatchers (finish up) OSB Staff	Music Lauri and TomReese
10:45 a.m. - 11:30 a.m.	Music ♫ Lauri and Tom Reese	Quiet room OSB Staff	Pick up Masks	Pick up Puppets	Pick up Dreamcatchers	Child care and activities OSB Staff
11:45 a.m.	L	U	N	C	H	

Instructional Support System
of Pennsylvania
Pennsylvania Department of Education

WESTERN INSTRUCTIONAL SUPPORT CENTER

5347 William Flynn Highway
Gibsonia, PA 15044-9644
412-961-0294, toll free 800-446-5607
Fax 412-443-1310

MEMORANDUM

RE: Outreach project for VIISA, SKI*HI, and INSITE
TO: Early intervention providers and parents
FROM: Debby Oppel Holzapfel, PennTech Consultant - Visual Impairment
Juli Baumgarner, Education Consultant - PA Deaf-Blind Project
Anita Iurlano, PennTech Consultant - Hearing Loss
DATE: August 19, 1996

Enclosed is information regarding an early intervention outreach project for children with sensory impairments. Local and state-wide workshops are planned for VIISA (visual impairment), INSITE (dual sensory impairment), and the SKI*HI (deaf and hard of hearing) models. Additionally, local workshops may be planned at the request of early intervention agencies. This is part of an outreach project intended to support local capacity, and is co-sponsored by PennTech, the Pennsylvania Deaf-Blind Project, and Early Intervention Technical Assistance.

You are encouraged to call the contact persons listed in the attachments, if you have further questions. Thank you.

Attachments:
VIISA Project Announcement
SKI*HI Project Announcement
INSITE Project Announcement
Chart Summary of Projects

VIISA Project

Sponsored by

PennTech, WISC and Early Intervention Technical Assistance (formerly FFEIS)

VIISA Project

The VIISA Project was developed by SKI-HI Institute at Utah State University. The purpose of the project is to provide inservice training to early intervention and early childhood professionals working with children ages birth to five who are blind and visually impaired and their families in a variety of early intervention settings.

The format of the inservice training involves two separate courses. An Infant Course and a Preschool Course. Each course involves four days of on-site sessions (two days at a time) and homestudy assignments in between the two on-site sessions. Participants need to plan to attend all four on-site days and complete homestudy assignments.

Who Should Attend?

Early childhood and early intervention professionals, consultants and educators of children with visual impairment, preschool teachers, infant specialists, developmental specialists, home visitors, family members and others.

Inservice Format

The format for each course will consist of:

- An initial home study assignment;
- An initial 2 day on-site class;
- Seven - eight assignments and readings (located in theHome Study Manual) to be completed and mailed to the trainer for feedback and to be submitted at the end of the course in the form of a portfolio;
- A final 2 day on-site class, approximately 10 - 12 weeks after the first one;
- Content and skills taught through lecture, video, discussions, small group application of case studies, observation, and practical experiences.

Course Descriptions

Infant Course (Course One)

The Infant Course (Course One) focuses on early intervention for infants and toddlers with blindness and visual impairments and their families.

Program Objectives

At the conclusion the participants will:

- be familiar with the unique needs of infants and toddlers who are visually impaired and their families
- gain basic knowledge of how to work with families

- know how to observe and assess the needs of infants and toddlers and develop IFSPs
- become familiar with how to access services, resources, and supports for transition
- gain basic knowledge of intervention techniques, curricula, and materials

Content Areas

- vision impairments/effects/ medical information
- vision development
- communication/socialization
- families and service delivery options
- motor and orientation and mobility
- touch and hearing
- cognition and play
- routines
- other impairments/prematurity
- assessments, IFSP, transitions

Preschool Course (Course Two)

The Preschool Course (Course Two) focuses on preschoolers ages three through five with blindness and visual impairments in educational and community settings.

Program Objectives

At the conclusion the participants will:

- be familiar with the unique needs of preschoolers who are visually impaired;
- know how to observe and assess the needs of preschoolers and develop IEPs;
- become familiar with how to access services, resources, and supports for transition;
- gain basic knowledge of intervention techniques, curricula, and materials;
- gain understanding of needed compensatory skills, socialization, school readiness and behaviors unique to the child with visual impairment.

Content Areas

- center-based setting with preschoolers
- daily living skills/socialization skills
- cognition and concept development
- orientation and mobility
- additional impairments
- keeping family involved
- assessments and IEPs
- transitions and elementary school placements

For More Information

Contact Debby Oppel Holzapfel at 1 800 446 5607 ext. 222 (in PA only) or 412 961 0294 ext. 222.

Training Dates, Locations, and Times

Western Area

Infant Course (Course One)
Monday and Tuesday, November 11-12, 1996
Thursday and Friday, January 30-31, 1997
(Snowdate Thursday and Friday, February 13-14, 1997)

Preschool Course (Course Two)
Thursday and Friday, February 20-21, 1997
(Snowdate Thursday and Friday, March 13-14, 1997)
Thursday and Friday, May 8-9, 1997

Time 9:00 AM - 4:30 PM

Location
Westmoreland Intermediate Unit 7, Greensburg, PA

Eastern Area

Infant Course (Course One)
Friday and Saturday, October 4-5, 1996
Friday and Saturday, December 6-7, 1996

Preschool Course (Course Two)
Friday and Saturday, March 7-8, 1997
Friday and Saturday, May 2-3, 1997

Time 9:00 AM - 4:30 PM

Location
Bucks County Intermediate Unit 22, Doylestown, PA

Registration Information

- Pre-registration is required to insure course materials are mailed in advance of the course so that you may complete the first home study assignment and preview the manuals.

- Registration is limited to a maximum of 30 participants.

- You must attend both on-site classes and complete the home study assignments.

- There is no registration fee.

- If you cancel, please allow WISC enough time to notify someone who may be on a waiting list.

- Lunch is at cost. We will make arrangements on the training day to be most efficient.

- For more information contact Debby Oppel Holzapfel at 1 800 446 5607 ext. 222 (in PA only) or 412 961 0294 ext. 222.

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- If you have special needs as addressed by the Americans with Disabilities Act and need assistance during any of these trainings, notify Ethel Silliman at the Western Instructional Support Center by phone at 1 800 446 5607 ext. 250 (in PA only), 412 961 0294 ext. 250 (V), 412-443-1310 (FAX) or 412-443-0671 (TTY). Reasonable efforts will be made to accommodate you.

REGISTRATION FORM FOR VIISA PROJECT

Please print or type the following information.

DATE/LOCATION you will attend ______________________________

NAME ______________________________

ROLE/ JOB ASSIGNMENT ______________________________

FACILITY ______________________________

(Please check __, if this is your home address.)

ADDRESS ______________________________

CITY/STATE/ZIP ______________________________

PHONE DAYTIME ______________ SCHOOL DISTRICT ______________

Please indicate if you need:
__ Oral Interpreter
__ PSE/ASL Interpreter
__ Amplification System, please specify ______________
__ Materials Accommodation
__ Other, please specify ______________

Mail this form to:

Ethel Silliman/VIISA
Western Instructional Support Center
5347 William Flynn Highway
Gibsonia, PA 15044

SKI*HI Project

Sponsored by

PennTech, WISC and Early Intervention Technical Assistance (formerly FFEIS)

SKI*HI Project

The SKI-HI Project was developed by SKI-HI Institute at Utah State University. The purpose of the project is to provide inservice training to early intervention and early childhood professionals working with children ages birth to five who are deaf or hard of hearing and their families in a variety of early intervention settings. Because hearing loss has a profound effect on a child's communication and language development, early intervention by trained professionals is critical.

Who should attend?

Early childhood and early intervention professionals, consultants and educators of children who are deaf or hard of hearing, preschool teachers, infant and developmental specialists, home visitors, family members and others.

Program Objectives

At the conclusion the participants will:

- be familiar with the unique needs of infants, toddlers and preschoolers who are deaf or hard of hearing and their families
- be familiar with the SKI-HI rationale for early home intervention and the major components of the SKI-HI program
- expand their skills in working in partnership with families using SKI-HI resources to develop information and skills for helping the child progress
- know how to observe and assess the needs of infants, toddlers and preschoolers and develop IFSPs or IEPs setting relevant goals and an implementation process
- become familiar with how to access services, resources, and supports for transition
- gain basic knowledge of intervention techniques, curricula, and materials

Inservice Format

The format for each course will consist of:

- An initial home study assignment
- An initial 2 day on-site class
- Seven assignments and readings (located in the Independent Home Study Manual) to be completed and mailed to the trainer for feedback prior to the final 2 day on-site class
- A final 2 day on-site class, approximately 10 - 12 weeks after the first one
- Content and skills taught through lecture, video, discussions, small group application of case studies, observation, and practical experiences.
- Submission of the eight home study assignments in the form of a portfolio at the end of the course

Training Dates, Locations and Times

Fall Session
Friday and Saturday, September 20 & 21, 1996 and December 6 & 7, 1996 at PennTech, Harrisburg

Spring Session
Friday and Saturday, February 21 & 22, 1997 and May 16 & 17, 1997 at the Western Instructional Support Center, Pittsburgh.

Times 9: 00 AM to 4:30 PM

For More Information

Contact Anita Iurlano at 1 800 446 5607 ext. 221 (in PA only) or 412 961 0294 ext. 221.

Registration Information

- Pre-registration is required to insure course materials are mailed in advance of the course so that you may complete the first home study assignment and preview the manuals.

- Registration is limited to a maximum of 25 participants.

- You must attend both on-site classes and complete the eight home study assignments.

- There is no registration fee. If you cancel, please allow WISC enough time to notify someone who may be on a waiting list. Lunch is on your own; you may bring a brown bag or we will order in so as to be most efficient.

- To begin the course you will need copies of the 1993 Edition of the SKI-HI Model-A Resource Manual for Family-Centered Home-Based Programming for Infants, Toddlers and Preschool Aged Children with Hearing Impairments (Item #103), SKI-HI Summary and Challenge Sheets (Item #300) and SKI-HI Language Development Scale (Item #401). The cost of the materials is $117.20 (includes 10% Shipping and Handling). You can order the materials from Hope, Inc., 55 East 100 North, Suite 203, Logan, UT 84321, (801) 752-9533 (phone/fax). Materials for the Fall Session Course may be borrowed from the project and will be mailed to participants in late August. These materials must be returned to the project at the completion of the course.

- For more information contact Anita Iurlano at 1 800 446 5607 ext. 221 (in PA only) or 412 961 0294 ext. 221.

- If you have special needs as addressed by the Americans with Disabilities Act and need assistance during any of these trainings, notify Ethel Silliman at the Western Instructional Support Center by phone at 1 800 446 5607 ext. 250 (in PA only), 412 961 0294 ext. 250 (V), 412-443-1310 (FAX) or 412-443-0671 (TTY). The Pennsylvania Relay Center TDD users number is 1-800-654-5984. Reasonable efforts will be made to accommodate you.

REGISTRATION FORM FOR PROJECT SKI-HI

Please print or type the following information.

DATE/LOCATION you will attend ______________________________

NAME ______________________________

ROLE/ JOB ASSIGNMENT ______________________________

FACILITY ______________________________

(Please check __, if this is your home address.)

ADDRESS ______________________________

CITY/STATE/ZIP ______________________________

DAYTIME PHONE ______________ SCHOOL DISTRICT ______________

Please indicate if you need:
- __ Oral Interpreter
- __ PSE/ASL Interpreter
- __ Amplification System, please specify ______________
- __ Materials Accommodation
- __ Other, please specify ______________

Mail this form to:

Ethel Silliman
Western Instructional Support Center
5347 William Flynn Highway
Gibsonia, PA 15044

INSITE Project

presented by
Pennsylvania Deaf-Blind Project and
Early Intervention Technical Assistance (formerly FFEIS)

INSITE Project

The INSITE Project was developed by the SKI*HI Institute of Utah State University. The INSITE model is a comprehensive intervention model for families of children who have multiple disabilities and sensory impairment, including children who are deaf-blind, between the ages of birth and five years. The training prepares professionals to be parent advisors helping families acquire information, skills and support in facilitating the development of their young children who have sensory impairments combined with other handicaps. The training includes a comprehensive overview of the rationale and organization of the INSITE model, including early identification, administration and supportive service components.

Who should attend?

Early childhood and early intervention professionals, consultants and educators of children who are deaf or hard of hearing, consultants and educators of children who are visually impaired or blind, consultants and educators of children who are deaf-blind, preschool teachers, infant and developmental specialists, home visitors, family members and others.

Program Objectives

At the conclusion the participants will:

- be familiar with the unique needs of infants, toddlers and preschoolers with multiple and sensory impairments, including deaf-blindness
- be familiar with the INSITE rationale for early home intervention and the major components of the INSITE program
- expand their skills in working in partnership with families using INSITE resources to develop information and skills for helping the child progress
- know how to observe and assess the needs of infants, toddlers and preschoolers and develop IFSPs or IEPs setting relevant goals and an implementation process
- gain basic knowledge of intervention techniques, curricula, and materials for communication, audition, vision, motor, self care, cognition
- accomplish other goals determined through local needs

Inservice Format

The format for each course will consist of:

- An initial home study assignment
- An initial 2 day on-site class
- Assignments and readings to be completed and mailed to the trainer for feedback prior to the final 2 day on-site class
- A final 2 day on-site class, approximately 10 - 12 weeks after the first one
- Content and skills taught through lecture, video, discussions, small group application of case studies, observation, and practical experiences.

- Submission of the home study assignments in the form of a portfolio at the end of the course

Training Dates and Locations

Training will be arranged at the request of local agencies. A priority exists to provide training in local areas, and to agencies serving families and their children who are deaf-blind, or who are at-risk for deaf-blindness.

A fall 1996 session is scheduled in the Pittsburgh area at a local agency. A limited number of addditional participants may be added to this workshop. Please call Juli Baumgarner or Mary Frey (listed below) for more information.

For More Information

Contact Juli Baumgarner at 800-446-5607 ext. 238 (in PA only) or 412-961-0294 ext. 238; or Mary Frey at 800-360-7282 or 717-541-4968.

Registration Information

- Pre-registration is required to insure course materials are mailed in advance of the course so that you may complete the first home study assignment and preview the manuals.

- Registration is limited to a maximum of 25 participants.

- You must attend all on-site classes and complete the home study assignments.

- There is no registration fee. If you cancel, please allow us enough time to notify someone who may be on a waiting list. Lunch is on your own; you may bring a brown bag or we will order in so as not to disrupt the training.

- Due to limited financial resources, we will ask participants to bring manuals from their agencies, or to share. If this is not feasible, materials may be loaned from the Deaf-Blind Project.

- If you have special needs as addressed by the Americans with Disabilities Act and need assistance during any of these trainings, notify Nancy Lehr at PennTech by phone/TDD at 800-360-7282 (PA only) or 717-541-4960, or 717-541-4968 (FAX). The Pennsylvania Relay Center TDD users' number is 1-800-654-5984. Reasonable efforts will be made to accommodate you.

PENNSYLVANIA OUTREACH PROJECT FOR EARLY INTERVENTION: VIISA, SKI•HI, INSITE

Goals: To enhance local capacity of agencies to provide services to young children with sensory impairments.

To support at least one person in each intermediate unit area who is skilled in providing outreach services for children with hearing loss, visual impairment, and/or dual sensory impairment

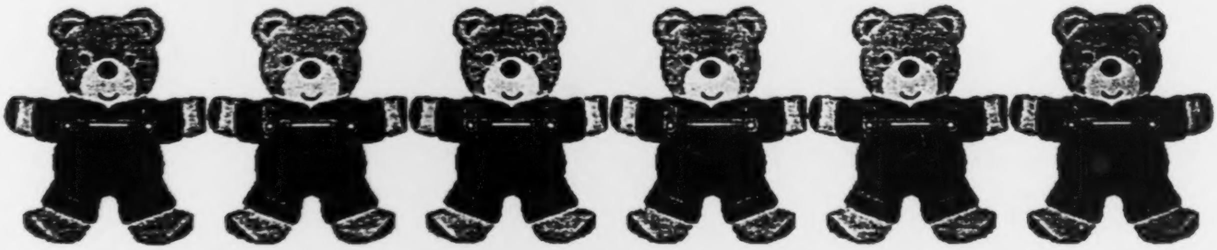
	VIISA	SKI•HI	INSITE
Target	children with visual impairment or blindness	children who are deaf of hard of hearing	children with multiple and sensory impairment, including deaf-blindness
Age	birth to five years	birth to five years	birth to five years
Format	• four days training (each for infant and preschool courses) • pre-assignment and mid-course home study assignments • portfolio • three months duration	• four days training • pre-assignment and mid-course home study assignments • portfolio • three months duration	• four days training • pre-assignment and mid-course home study assignments • portfolio • three months duration
Content	Course 1 (Infant course) • vision impairments/effects/ medical information • vision development • communication/socialization • families and service delivery options • motor and orientation and mobility • touch and hearing • cognition and play • routines • other impairments/prematurity • assessments, IFSP, transitions Course 2 (Preschool course) • center-based setting with preschoolers • daily living skills/socialization skills • cognition and concept development • orientation and mobility • additional impairments • keeping family involved • assessments and IEPs • transitions and elementary school placements	• home-based early intervention • communication • auditory programming • language development -aural-oral language -total communication -American Sign Language • working with families • assessment, setting goals, and planning	• home-based early intervention • communication • motor impairments • hearing • vision • cognition • developmental resources • working with families • assessment, setting goals and planning • other topics specific to local needs

	VIISA	SKI*HI	INSITE
Outreach	local trainers supported by PennTech, EITA, and other VIISA trainers	local trainers supported by PennTech and EITA	local support people, mentored by State INSITE trainers, PA Deaf-Blind Project, EITA, and local people previously trained in INSITE
Materials	supplemental resources available on loan from PennTech limited amount of curriculum materials available for use by agencies	supplemental resources available on loan from PennTech limited amount of curriculum materials available for use by agencies	supplemental resources available on loan from PennTech/PA Deaf-Blind Project limited amount of curriculum materials available for use by agencies
Network/ Support	Support available during training period and after training Contact Debby Holzapfel (800-446-5607, ext. 222) for information regarding training opportunities, local resources, and support	Support available during training period and after training Contact Anita Iurlano (800-446-5607, ext. 221) for information regarding training opportunities, local resources and support	Support available during training period and after training Contact Juli Baumgarner (800-446-5607, ext. 238) or Mary Frey (800-360-7282) for information regarding training opportunities, local resources and support

Strategies for Working with Young Children with Sensory Impairments

Mary Frey
Pennsylvania Deaf-Blind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
(800) 360-7282

Mary Anketell
Early Intervention Technical Assistance
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
(800) 360-7282



BEGINNING COMMUNICATION WITH INFANTS, TODDLERS, AND PRESCHOOL AGE CHILDREN WHO HAVE SENSORY AND/OR MULTIPLE IMPAIRMENTS

◆

Mary R. Frey
Education Consultant
Pennsylvania Deafblind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
800-360-7282 (PA only)
717-541-4960

◆

Annual Family Learning Retreat

The PA Deafblind Project's Educator Learning Day (June 25) is being held in conjunction with the Annual Family Learning Retreat "Together We're Better: Learning Through Play and Humor" on June 25, 26, 27, 1999. Parents are invited to join educators for the day in "Shared Experiences: Increasing Literacy and Communication Opportunities for Children With Deafblindness."

PA Deafblind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
800-360-7282 in PA only

BEST COPY AVAILABLE

PA Deafblind Project

Shared Experiences: Increasing Literacy & Communication Opportunities for Children With Deafblindness

Educator Learning Day

Friday, June 25, 1999
Holiday Inn-Harrisburg/Hershey

Shared Experiences: Increasing Literacy & Communication Opportunities for Children With Deafblindness

⇒ Shared experiences can be used as strategies to increase opportunities for literacy and communication for children with deafblindness.

⇒ Enriching and documenting shared experiences promote meaningful activities for learning and literacy.

⇒ Reading & writing stories with adaptation & accommodations are applicable for children with deafblindness from toddlers to teens with a variety of communication modes at emergent & early levels of literacy.

Outcomes of the workshop:

- ◊ Understand the rationale for shared experiences.
- ◊ Construct calendar box, schedule box or sequence board.
- ◊ Develop templates for experience books or object books.
- ◊ Network with colleagues and parents.

Schedule

8:30 AM - Registration & Coffee

9:00 AM - Overview

Rationale

- Application

11:45 AM - Lunch (provided)

12:45 PM - Make It/Take It Stations

- Action Planning

- Evaluation

4:00 PM - Conclusion

(can continue to make items until 5:00 PM)

5:00 PM - Dinner (provided)

Facilitator

Therese Rafalowski Welch is a national consultant in the areas of deafblindness and multiple disabilities. She has worked as a classroom teacher, an itinerant instructor, state vision consultant and state deafblind program administrator.

Registration

Please return by May 21, 1999.

I plan to participate...

☐ 9:00 AM – noon
☐ 1:00 – 4:00 PM
☐ Evening Activities

I plan to eat at the hotel

☐ Lunch – 11:45 AM -12:45 PM
☐ Dinner – 5:00 – 6:00 PM

I wish to know more about...

☐ Calendar/schedule box
☐ Experience stories
☐ Object Books
☐ Tangible symbols/cues
☐ Adapting stories

I have attended Quarterly Institutes:
Literacy for Students with Sensory Impairments

☐ August/September 1998
☐ November 24, 1998
☐ February 17, 1999

Comments:

Name

Role and Agency Name

Home Address

Phone number in June. Best time to call.

PA Deafblind Project

6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
800-360-7282 in PA only

Phone: 717-541-4960
Fax: 717-541-4968
Email: nlehr@cisc.k12.pa.us

Welcome!

Shared Opportunities:
Increasing Literacy and Communication Opportunities for Children with Deafblindness

Welcome to the fourth workshop in a series of quarterly institutes - Literacy for Students with Sensory Impairments sponsored by the PA Deafblind Project!

The Project is quite excited to have Carolyn Monaco as our guest speaker. Carolyn has worked as an instructor and consultant in the field of deafblindness for 21 years in Canada and internationally. She also provides training for intervenors at George Brown College on a part time basis. The Project hopes to welcome her back to Pennsylvania over the next few years to provide intervenor training for paraeducators who work with individual students with deafblindness.

Participating today is a wonderful blend of parents, guardians, educators, paraeducators, early interventionists, consultants, occupational therapists, and speech/language pathologists. Please take advantage of the opportunity to exchange knowledge and share skills as you work on experience books.

You are receiving a certificate of participation from the Project for the workshop. A total of .6 CEU (continuing education units) are available from the Pennsylvania College of Optometry for a fee.
Enjoy your day!

I would like to thank: Margie Briley for being available to facilitate the day! Jeanne Beck-Gardier and Kathy Scott for providing childcare activities! Nancy Lehr for working on details - registration, materials, handouts, etc.! Judy and Stephanie Carl for whatever needed to be done at the moment!

Mary R. Frey

Wonderful Opportunity!

Deafblind Education: A Path for Communication, Instruction, and Positive Behavior Support

Penn State University

Monday August 9	Tuesday August 10	Wednesday August 11	Thursday August 12	Friday August 13
morning	*morning*	*morning*	*morning*	*morning*
Foundations of Deafblind Education Stephanie McFarland	Enhancing Communication Skills in Students Who Are Deafblind Stephanie McFarland	Enhancing Communication Skills in Students Who Are Deafblind Stephanie McFarland	Establishing Positive Behavioral Support for Students Who Are Deafblind Anne Malatchi	Instructional Design and Learning Techniques Chigee Cloninger, Susan Edelman
afternoon	*afternoon*	*afternoon*	*afternoon*	*afternoon*
Foundations of Deafblind Education Stephanie McFarland	Enhancing Communication Skills in Students Who Are Deafblind Stephanie McFarland	Establishing Positive Behavioral Support for Students Who Are Deafblind Anne Malatchi	Instructional Design and Learning Techniques Chigee Cloninger, Susan Edelman	Instructional Design and Learning Techniques Chigee Cloninger, Susan Edelman

* For registration details or more information, contact the PA Deafblind Project at 1.800.360.7282 ext. 3115 (PA only) or 1.717.541.4960 ext. 3115.

Participants are encouraged but not required to attend this active training as teams. PA teams may be eligible for monthly onsite visits and follow-up training by education consultants during the 1999-2000 school year. Cost for the course is minimal. Learning Awards available to assist with costs, if needed. The Deafblind Education course is being held in conjunction with the Summer Autism Institute and in partnership with the PA Department of Education and Penn State University, College of Education.

ATTN:
Parents, educators, service providers, paraeducators, therapists

One week course on Deafblind Education!

Wonderful opportunity to learn about children with combined vision and hearing impairments, to network with others who educate and provide services to the children, to interact with family members of the children.

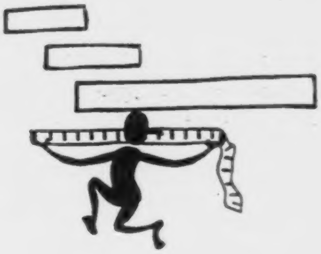
PA Deafblind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764

Please share with others who may benefit from this information. Thanks!

Deafblind Education: A Path to Communication, Positive Behavior

General agenda

Monday, August 9, 1999
all day
Stephanie MacFarland, Ph.D.
Foundations of Deafblind Education



Tuesday, August 10, 1999
all day
Stephanie MacFarland, Ph.D.
Enhancing Communication Skills in Students Who Are Deafblind

Wednesday, August 11, 1999
morning
Stephanie MacFarland, Ph.D.
Enhancing Communication Skills in Students Who Are Deafblind (continued)

afternoon
Anne Malatchi, M.A.
Establishing Positive Behavioral Support for Students Who Are Deafblind

Thursday, August 12, 1999
morning
Anne Malatchi, M.A.
Establishing Positive Behavioral Support for Students Who Are Deafblind (continued)

afternoon
Chigee Cloninger, Ph. D. Susan Edelman, Ed. D.
Instructional Design and Learning Techniques

Friday, August 13, 1999
all day
Chigee Cloninger, Ph. D. Susan Edelman, Ed. D.
Instructional Design and Learning Techniques (continued)

Each day, there is a scheduled morning break, a lunch break, and an afternoon break. Dinner is on your own, except for Thursday. The PA Deafblind Project is sponsoring a dinner.

Local Transition Team Training #4

PennTech, Harrisburg

co-sponsored by :
The PA Deaf-Blind Project and
The Helen Keller National Center - Technical Assistance Center

Agenda

Tuesday, October 8, 1996

12:30 - 1:00p.m.	Registration - Conference Rooms A/B
1:00 - 1:15 p.m.	Ice breaker
1:15 - 2:00 p.m.	Introduction to State/Community Team Partnerships
2:00 - 2:30 p.m.	Key Aspects of Interagency Collaboration
2:30 - 2:45 p. m.	Break
2:45 - 3:45 p.m.	Mission and Team Goals
3:45 - 5:15 p.m.	Meeting Effectiveness - Nuts and Bolts Action Planning
5:15 - 5:30p.m.	Kaizen - Evaluation
6:00 p.m.	Dinner at Best Western Country Oven Dining Room

Agenda

Wednesday, October 9, 1996

8:30 - 9:00 a.m.	Registration, informal gathering of old/new team members
9:00 - 10:30 a.m.	State Team - introduce members Cohort highlights Sharing - Team Updates Discuss date, format of LTT #5
10:30 - 10:45 a.m.	Break
10:45 - 11:15 a.m.	"Transition Connections: Planning Today -- Creating Tomorrow"
11:15 a.m.- 12:45p.m.	IDEA Guidelines Informal Assessments Housing Natural Supports Parent Survey, Vocation Training Post Secondary Training Funding Changes with Assistive Technology, Survey Info Funding Booklet Funding Sources for Employment (supported vs competitive)
12:45 - 1:30 p.m.	Lunch
1:30 - 2:30 p.m.	"Participating in your own I.E.P." Person-centered Transition, Statement of Transition Forms Connection between instructional areas and I.E.P. and Transitional Plans: Current PA format Banking Diplomas Team Plan: application and planning
2:30 - 3:15 p.m.	Team Self-evaluations Team Action Planning Report Back
3:15 -3:30 p.m.	Kaizen, Satisfaction Evaluation of Training PennTech evaluations
3:30 p.m.	Have a safe trip home !

MRF/8-15-96/LTT

DRAFT AGENDA

DRAFT AGENDA

TRANSITION TRAINING

NOVEMBER 12, 1998

9:15 – 9:45	Registration and Coffee
9:45 – 10:30	Introductions and Opening Remarks
10:30 – 11:10	Dr. Paul Loera, Center on Deafness, Western PA School for the Deaf
11:10 – 11:30	Q & A with Dr. Loera
11:30 – 11:45	Team Sharing for those teams using MH input: What's Working, What's Not
11:45 – 12:15	Case Study Outcomes Map
12:15 – 1:00	Lunch
1:00 – 1:30	What are we Learning?
1:30 – 2:30	Report Out: Focused Feedback on Case Study Outcomes Map
2:30 – 2:50	Action Plan and Set Next Date
2:50 – 3:00	Kaizen

Instructional Support System
of Pennsylvania
Pennsylvania Department of Education

WESTERN INSTRUCTIONAL SUPPORT CENTER
5347 William Flynn Highway
Gibsonia, PA 15044-9644
724/443-7821, Toll Free: 800/446-5607 (PA Only)
Fax: 724/443-1310 • TTY 724/443-0671 (PA Relay)
E-Mail: wisc@wisc.org
http://www.wisc.org/

Second Quarterly Institute for Educators
Serving Students with Sensory Impairment/Low Incidence

Literacy for Students with Visual Impairments

Videoconference

November 24, 1998

Sponsored by: The Instructional Support System of Pennsylvania

Presenters:

Meryl Lazar, Ph.D., Institute for Practice and Research,
School of Education, University of Pittsburgh

Kathleen Jacobs Shoop, Learning Research and Development Center,
University of Pittsburgh

Agenda

8:45 Teaching Reading and Writing (see outline)

11:45 Lunch

12:45 How does this information relate to teachers of students with visual impairments?

Action plan review with site facilitator with teachers of students who are deaf and hard of hearing.

1:45 How does this information relate to teachers of students who are deaf and hard of hearing?

Action plan review with site facilitator with teachers of students with visual impairments.

2:45 Debriefing, action planning and evaluation

Quarterly Institutes for Educators Serving Students with Sensory Impairments/Low Incidence

What are the Quarterly Institutes?

- An ongoing series of interactive trainings which will focus on Literacy and Students with Sensory Impairments which will take place four times throughout the 1998-99 school year.
- They will be provided for low incidence service providers in order to address the Governor's Agenda concerns, IDEA 1997 and the needs of the field.
- Graduate credits and continuing education units are available.

Expected Outcomes

- Students with sensory impairment receive appropriate services and supports.
- Sufficient number of trained personnel are available to provide services.

Who May Benefit?

- Service providers serving students with visual impairments, students who are deaf and hard of hearing, and students who are deafblind

Theme: Literacy for Students with Sensory Impairments

Goals

- Address assessment, instruction and support strategies implementing adult learning principles in order to identify strategies that will ensure more success in communication, reading and writing skills for students with sensory impairments/low incidence.
- Promote a broader sense of literacy for all students with sensory impairments.
- Utilize assessment and observation skills used to evaluate appropriate literacy tools.
- Introduce and adapt literacy activities for all learners.

First Quarterly Institute

Statewide held in Pittsburgh Area	August 18 - 20, 1998
Eastern Area	September 22 - 24, 1998
Statewide Educational Interpreters	August 17 - 20, 1998

This statewide Educational Interpreters training is offered to those who have taken the Educational Interpreter Performance Assessment (EIPA) training and will address skill areas that need development.

Second Quarterly Institute	November 24, 1998	8:45 AM - 3:15 PM
Third Quarterly Institute	February 17, 1999	8:45 AM - 3:15 PM
Fourth Quarterly Institute	June 8, 1999	8:45 AM - 3:15 PM

The second, third and fourth quarterly institutes will be held at Western Instructional Support Center, Central Instructional Support Center, and Eastern Instructional Support Center utilizing videoconference and interactive learning.

First Quarterly Institute

Focus I - Literacy and Students with Sensory Impairments

Who should attend?

- Educators in the field of deaf and hard of hearing
- Educators in the field of visual impairment
- Educators of students with dual sensory impairments

Areas to be covered

- Assessing "visual listening" skills and acquiring visual storytelling strategies
- Assessing learning media through interactive learning
- Observations tools
- Providing good assessment information for the comprehensive evaluation report (CER) and individualized education program (IEP) that flows one from to the other
- Broader sense of literacy for all students
- Practice and implement skills learned
- Customized action plans for follow-up

A. Pittsburgh Area

When August 18 - 20, 1998

Tuesday	12 PM - 5 PM (registration 10:30 -12:00, lunch available)
Wednesday	8 AM - 5 PM
Thursday	8 AM - 12 PM

Where

Western Pennsylvania School for Blind Children
201 North Bellefield Avenue
Pittsburgh, PA 15213
412-621-0100

Directions/map will be sent upon request on registration form.

Costs

Some costs for housing and meals will be supported by Pennsylvania Department of Education, Bureau of Special Education, through the Instructional Support System.

No cost for **housing** if staying at Western Pennsylvania School for Blind Children, WPSBC, (dormitory setting with air conditioning, linens and parking provided; a mirror, hangars and lock are suggested; doors lock at 11:00 PM). Make reservation only on form provided through Western Instructional Support Center and not with WPSBC.

Accommodations are also available (at your own cost) at the Holiday Inn University Center in Oakland for $84.00 per night, 14% tax, and parking at $14 per day prior to July 27. You must make you own reservation by calling 412-682-6200 and indicate you are with Literacy and Students with Sensory Impairments/Debby Holzapfel. Guests must also present "notice" obtained from Debby Holzapfel. If reservations are made after July 27, group rate will not apply and cost will be $139.95 plus 14% tax and $14 per day parking.

All **meals** provided at Western Pennsylvania School for Blind Children are at no cost.

Reservations for rooms and meals must be made through registration form and not through WPSBC.

Transportation is not included.

Credits

Graduate level credits are available from the University of Pittsburgh at a cost of $317 per credit (3-4% increase expected July 1), $35 application fee and $18 associated fees.

Continuing education units are available through:

- University of Pittsburgh for $150 with no certificate; or
- Pennsylvania College of Optometry at a cost of $35 with a certificate.

The first quarterly institute is available for one credit; involvement throughout the year will provide 2 credits. One credit per 15 hours in classroom time and two credits per 30 hours are available throughout the year.

B. Eastern Area - Eastern Instructional Support Center

When September 22 - 24, 1998

Tuesday	9 AM - 3:30 PM (registration 8 - 9 AM)
Wednesday	9 AM - 3:30 PM
Thursday	9 AM - 3:30 PM

Where
Eastern Instructional Support Center
200 Anderson Road
King of Prussia, PA 19406
800-441-3215

Directions/map will be sent upon request on registration form..

Costs

Lunch will be provided at Eastern Instructional Support Center.

No overnight accommodation costs will be covered.

Accommodations are available at the Hampton Inn in King of Prussia for $83 per night with 8% tax. You must make you own reservation by calling 610 962 8111 and indicate you are with Literacy and Students with Sensory Impairments/Debby Holzapfel. Guests must also present "notice" obtained from Debby Holzapfel.

Transportation is not included.

Focus II

Who should attend?

Educational Interpreters who have taken the Educational Interpreter Performance Assessment (EIPA)

Outcomes

- Participants shall understand at least 3 major factors contributing to the understandability of a whole message
- Participants shall begin to apply these major factors to their own interpreting
- Participants shall learn tools for developing these factors at home

When August 17 - 20, 1998 (statewide)

Monday	9 AM - 4 PM (registration 8 - 9 AM, lunch available each day)
Tuesday	9 AM - 4 PM
Wednesday	9 AM - 4 PM
Thursday	9 AM - 4 PM

Where

Western Pennsylvania School for Blind Children area
201 North Bellefield Avenue
Pittsburgh, PA 15213
412-621-0100

Directions/map will be sent upon request on registration form.

Costs

No cost for **housing** if staying at Western Pennsylvania School for Blind Children, WPSBC, (dormitory setting with air conditioning, linens and parking provided: a mirror, hangars and lock are suggested; doors lock at 11:00 PM). Make reservation only on form provided through Western Instructional Support Center and not with WPSBC.

Accommodations are also available at the Holiday Inn University Center in Oakland for $84.00 per night, 14% tax and parking is $14 per day prior to July 29. You must make you own reservation by calling 412-682-6200 and indicate you are with Literacy and Students with Sensory Impairments/Debby Holzapfel. Guests must also present the "notice" obtained from Debby Holzapfel. If reservations are made after July 27, group rate will not apply and cost will be $139.95, plus 14% tax and $14 per day parking.

All **meals** provided at Western Pennsylvania School for Blind Children at no cost. Reservation must be made through registration form and not through WPSBC.

Transportation is not included.

Credits **Continuing education units** are available through

- University of Pittsburgh for $150 with no certificate.\
- RID
- ACET

SHARED EXPERIENCES: INCREASING LITERACY AND COMMUNICATION OPPORTUNITIES FOR CHILDREN WITH DEAFBLINDNESS

Pennsylvania Deafblind Project
Holiday Inn - Grantville

Friday 6/25/99	Educator Learning Day	Room
8:30 a.m.	Registration	Regency
9:00 - 11:45 a.m.	Child Care Activities	Pennsylvania
9:00 - 11:45 a.m.	Session: Overview, rationale, application	Regency
11:45 a.m.- 12:45 p.m.	Buffet Lunch	Garden Grille Restaurant
12:45 - 4:45 p.m.	Child Care Activities	Pennsylvania
12:45 - 4:00 p.m.	Session: Make It/Take It, Evaluation	Regency
4:00 - 4:45 p.m.	May continue Make It/Take It	Regency
4:45 p.m.	Pick up children from child care	Pennsylvania
5:00 - 6:30 p.m.	Dinner	Garden Grille Restaurant

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Continuing Education Units

Certificate of Participation

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From the Project

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Q & A About the Project

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Information About Braille

Summer Institute Registration

Information Update copy

Contact Information

Carolyn Monaco
Skills, Training & Resource Center, W. Ross Macdonald School
350 Brandt Avenue, Brantford, ON Canada N32 3J9
E-mail: carolyn.monaco@sympatico.ca
Work: 519-759-0730 ext. 262

06/22/99 PA Deafblind Project, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764
800-360-7282 (tollfree in PA only); 717-541-4960; web site: http://cisc.k12.pa.us

REGISTRATION INFORMATION

INTERAGENCY COLLABORATION: SUPPORTING STATE AND LOCAL TEAM PARTNERSHIPS FOR INDIVIDUALS WHO ARE DEAFBLIND

Who is invited?

Existing and newly formed transition teams for students with dual sensory impairments are invited. Teams may include parents, students who are deafblind, teachers, transition coordinators, representatives from community agencies such as MH/MR, BVS, or other local resources.

What is the purpose of the workshop?

Objectives are:

- promote awareness of mental health issues and potential strategies for individuals who are deafblind
- share successful team strategies regarding transition outcomes for individuals who are deafblind, and
- assist teams in implementing effective practices.

When and where is the workshop?

The workshop on November 12, 1998, from 9:15 a.m. to 3:00 p.m. will be held concurrently at:

Western Instructional Support Center -- Gibsonia, PA

And

Eastern Instructional Support Center -- King of Prussia, PA

Videoconference facilities as well as on-site discussions will allow teams to interact.

How do I register?

Please complete and return the enclosed registration form before October 30, 1998. If you have any questions about the purpose of the workshop, please call Juli Baumgarner (800.446.5607, ext. 238) or Mary Frey (800.360.7282, ext. 3005) at the Pennsylvania Deafblind Project. If you have questions about registration, location, etc., please call Nancy Lehr (800.360.7282, ext. 3115). Thank you.

Agenda: November 12, 1998

9:15 - 9:45	Registration and coffee
9:45 - 12:15	Introductions and opening remarks Mental health issues (guest speaker: Dr. Paul Loera from the Center on Deafness, Pittsburgh, PA) Team outcomes with the mental health system
12:15 - 1:00	Lunch (provided)
1:00 - 3:00	Case study outcomes (supported employment, supported living, recreation and leisure) Focused feedback on case study outcomes Team action planing

Pennsylvania Deafblind Project

JANUARY 24, 1998
Western Pennsylvania Regional Family Learning Day
Irwin, PA

Juli Baumgarner, Education Consultant
Molly Black, Family Consultant

10:00-	11:00	Registration
11:00-	11:15	Welcome, Introductions
11:15-	11:30	IDEA 97 and deafblindness
11:30-	12:00	Communication partners: Opportunities and responsiveness
12:00-	12:45	Lunch
12:45-	2:30	Video: Making the Most of Early Communication
2:30-	2:45	Behavior, Resources
2:45-	3:00	Discussion, Evaluations

You & Me

This workshop includes the topic of communication programming, the use of paraprofessionals to support students who are deafblind, and other aspects of deafblind education. Videotapes of Riley Ford, a student who is deafblind, will be viewed during the workshop. Discussion, written materials, and action planning will be used to help you apply what you have learned.

Educational programs succeed because of the coordinated commitment of team members -- home, school, community.

⁂ Your family is to encouraged to invite one person from your child's team ⁂
(e.g., teacher, therapist, nurse, aide, caretaker) to attend the workshop.

SCHEDULE:	9:00 a.m. - 10:00 a.m.	Registration and socializing
	10:00 a.m. - noon	Introduction to a student who is deafblind Role of the paraprofessional
	Noon	Buffet lunch (no cost)
	1:00 p.m. - 2:00 p.m.	Family activity
	2:00 p.m. - 3:00 p.m.	Communication: Choosing and Using
	3:00 p.m. - 4:00 p.m.	Applying what you've learned

Child care provided for children up to age 16.

APPLICATION DEADLINE: WEDNESDAY, SEPTEMBER 10, 1997

Detach and mail to: PA Deafblind Project, Attn: Nancy Lehr,
6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764

REGISTRATION

Name	Relationship (dad, sister, teacher, etc.)	Age (if under 21)	Wheelchair ✓	Highchair ✓	Booster seat ✓	Special needs: (medical, food, etc.)	West only hotel room-Fri. 9/26/97 ✓

BE SURE TO COMPLETE BOTH SIDES. → → → → → → → → → → → → → → →

PENNSYLVANIA
DEAFBLIND
PROJECT
INVITES YOUR
FAMILY TO . . .

REGIONAL
FAMILY
LEARNING
RETREAT
DAY

"YOU & ME"

Saturday
September 27, 1997

※※※※※

9:00 a.m. - 4:00 p.m.
(lunch provided)

SECOND NOTICE

PA DEAFBLIND PROJECT
C/0 CENTRAL INSTRUCTIONAL SUPPORT CENTER
6340 FLANK DRIVE, SUITE 600
HARRISBURG, PA 17112-2764

✂ -

Name ______________________________

Address ______________________________

____

Phone # (daytime) (   ) ______________________________

We wish to attend:

☐ East - Holiday Inn, Morgantown, Berks County
☐ West - Holiday Inn, Hermitage, Mercer County
Total # attending _____

You will receive a confirmation letter with directions to hotel and other details.

BE SURE TO COMPLETE BOTH SIDES. → → → → → → → → → → → → →

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Strategies for Learners who are Deaf-Blind

October 19, 1996
PA Deaf-Blind Project
at the Hermitage Holiday Inn

Presenters: Juli Baumgarner, Margaret Briley, Linda Critchlow

Learning Objectives:

- Participants will understand and plan to apply essential information about distance sensory impairments and how these impairments can affect students who are deaf-blind.
- Participants will understand the key role of family in the education of a student who is deaf-blind and the vital importance of a team approach.
- Participants will understand the vital role and many options for communication for students who are deaf-blind.
- Participants will understand and plan to apply strategies and adaptations for learning in the classroom and or home environment.

Agenda:

	Breakfast (only for those staying overnight on Friday) Use your voucher in the main restaurant.
9:30- 9:45	Registration
9:45-10:00	Introductions Overview
10:00-10:30	Characteristics of learners who are deaf-blind Exploring the environment
10:30-10:45	Break
10:45-11:15	Learning from your students Impact of vision and hearing on learning
11:15-12:15	Every child is a communicator
12:15- 1:15	Lunch
1:15- 2:00	A functional classroom environment
2:00- 2:15	Break
2:15- 2:45	It can be done!
2:45- 3:15	Action planning session
3:15- 3:30	Evaluations
3:45- 4:30	Dinner

**Instructional Support System
of Pennsylvania**
Pennsylvania Department of Education
Pennsylvania Department of Public Welfare

PENNTECH
6340 Flank Drive, Suite 600
Harrisburg PA 17112-2764
717-541-4960
Toll free 800-360-7282 in PA only
Fax 717-541-4968
TT 800-654-5984 (PA Relay)

Strategies for Learners who are Deaf-Blind

September 7, 1996
PA Deaf-Blind Project
at Overbrook School for the Blind

Presenters: Juli Baumgarner, Mary Frey

Learning Objectives:

- Participants will understand and plan to apply essential information about distance sensory impairments and how these impairments can affect students who are deaf-blind.
- Participants will understand the key role of family in the education of a student who is deaf-blind and the vital importance of a team approach.
- Participants will understand the vital role and many options for communication for students who are deaf-blind.
- Participants will understand and plan to apply strategies and adaptations for learning in the classroom and or home environment.

Agenda:

9:30-10:00	Registration
10:00-10:45	Introductions Overview
10:45-11:15	Characteristics of learners who are deaf-blind Exploring the environment
11:15-11:30	Break
11:30-12:00	Learning from your students
12:00- 1:00	Lunch
1:00- 1:20	Impact of vision and hearing on learning
1:20- 2:15	A functional classroom environment
2:15- 2:30	It can be done!
2:30- 2:45	Break
2:45- 3:25	Every child is a communicator
3:25- 3:45	Action planning session
3:45- 4:00	Evaluations

INFORMATION SHEET
Behavior Issues in Children With Multiple And Sensory Impairments

Children with multiple and sensory impairments may use unique or idosyncratic behaviors for a variety of reasons. When these behaviors interfere with the child's ability to learn about the world, it is necessary to examine the potential reasons for the behavior. Team meetings, functional behavior assessment, person-centered planning, and other tools may be used to help develop a plan to enhance the child's opportunities to learn. It is critical to consider effectiveness of communication and appropriate sensory input when focusing on behavioral issues for children with multiple and sensory impairments. This information can be combined with the FIVE-STEP PROCESS FOR POSITIVE BEHAVIOR SUPPORT. For more information about this process, or to request a copy of the Guidelines: Effective Behavior Support, please consult your Intermediate Unit Behavior Support Specialist or the PA Deafblind Project. Here is a very brief sample of the five-step process.

STEP 1. Conduct a functional assessment.

What happens before and after the behavior?

Is the behavior helping the child avoid a task?

Is the behavior used to gain attention?

Does the child have effective ways to communicate?

Are there any medical or physical causes?

STEP 2. Develop hypothesis statements.

"We think she bangs her head because she doesn't know what is next...."

STEP 3. Develop an effective behavioral support.

"To prevent head-banging, we will let her know what is next by using touch cues, object cues, and a calendar box. If she bangs her head, we will...."

STEP 4. Evaluation effectiveness.

"We will take data across different people and situations to see if she reduces head banging as she learns about her world through the touch cues, object cues, and a calendar box...."

STEP 5. Modify support plan as needed.

"We will increase consistency of responses to the child by training additional people to provide systematic input and to respond in consistent ways.

The following chart is a description of behaviors sometimes seen in children with sensory impairments. It is provided for you as an example, and is not meant to be exclusive of other information that a team may discover.

Unconventional Behavior	Possible Reasons	Practical Strategies
Head banging Body rocking	➢ Boredom ➢ Frustration ➢ Needs a break ➢ Need for stimulation due to sensory loss ➢ Limited opportunities to move around ➢ Not sure of what is happening	➢ Use routines to ensure participation. ➢ Analyze the potential communicative purpose(s). ➢ Help the child learn a "break" signal, symbol, sign or word. ➢ Accommodate and adapt for sensory loss. ➢ Use vestibular motion, when contextually appropriate, such as with a swing or rocking chair. ➢ Use cues or other input, matched to the child's sensory and communicative levels, to provide input about what is happening.
Eye poking	➢ Frustration ➢ Need for stimulation due to sensory loss ➢ Decreased sensation of pain ➢ Actual physical cause of pain	➢ Make sure that the child has chances to be successful. ➢ Introduce meaningful and interesting sensory stimuli. ➢ Use touch and movement activities. ➢ Always check for medical causes with family and medical personnel.
Hand biting	➢ Needs input to hand and mouth ➢ Frustration ➢ Needs something to do that is meaningful to him/her	➢ Help the child learn to use hands in functional ways. ➢ Introduce the activity, pace the activity, and help the child indicate when the activity is finished. ➢ Make sure the child is actively participating in the activity. ➢ Determine motivators and preferences for the child.

INFORMATION SHEET

Considerations in IEP Development for Children Who Are Deafblind

by Mary R.Frey, M.Ed., Education Consultant, Pennsylvania Deafblind Project

> *The IEP (Individualized Education Plan) is a written plan that tells what special education program and services the child will receive.The IEP is written at a conference by a team which includes the child's parents. ...An IEP must include all the programs and services necessary to meet the child's individual needs as identified during the evaluation or re-evaluation process.* (Mancuso, et. al., 1991, p.13.)

Before the IEP meeting

Assessment is an on-going process of information gathering. When formal and informal evaluation results are reviewed, they identify the child's needs and strengths. The information is the base for future directions of the IEP goals and objectives.

With a younger child, the INSITE checklist or Callier-Azuza is helpful. A number of personal futures planning tools, such as the MAPS or PATH processes can also be used to gather information - history, likes/dislikes, skills/needs, etc. - about the child who is deafblind. Identification of how the child receives information, preferred learning style, and modes of communication are considered.

Parents need access to therapy reports and other evaluative information before the IEP meeting is held so they have time to read, absorb, and question. Holding a preplanning meeting or phone calls with the rest of the IEP team members may be ways for all to share equally in voicing their concerns about the child and answering questions about the child's current status. Parents need to consider what the priorities for learning are for the child. Make note of the areas that evaluators found difficult for the child.

During the meeting

Family participation is integral to the IEP process and parents are to be active members of the team. Family members are the child's primary teachers. The child should participate in the actual conference to the best of his/her abilities. When it is not feasible for the child to be present, having a photograph on the table can remind the team to stay child-centered during the planning process.

When the team meets to discuss and write an IEP for a child who is deafblind, the impact of the dual sensory impairments upon the child and upon the methods of communication and instruction must be recognized. Efforts to promote the use of existing hearing and vision while providing appropriate accommodations throughout the plan are important. The IEP is to be functional, relevant, and age appropriate to the child.

Based on the child's needs while building upon the child's strengths, the team drafts both annual goals and short term learning outcomes. While the educational team members may have brought along written goals and objectives that they would like to be included, these are just suggestions. Rather than asking parents if they agree or disagree with pre-written objectives, meaningful and appropriate outcomes are to be discussed while considering family concerns and priorities. The IEP process is to be a joint effort.

> *IEP objectives do not forget isolated skills written by individual specialists on the team (e.g., vision specialist, hearing specialists, occupational therapists). Instead, these team members, along with family members, pool their expertise to create one IEP that includes objectives that are activity-based and reflect the numerous skills required by the activity. The team needs to identify the various opportunities to practice targeted IEP skills across different functional activities.* (Downing, 1996, p. 39, 41)

Developing language and communication skills is the overall theme, in many cases, in developing an IEP for a child who is deafblind. In the earlier years of a child's program, time spent exploring and trying a number of communication options and establishing the foundation of a communication system is prevalent. In later years, the focus tends to be on expansion of the communication system and increasing interaction with friends and classmates. Environmental cues enhance the child's full understanding of various situations, whatever the child's preferred method of communication.

Parents can question staff about the teaching methods that work best for their child. The IEP addresses skills that promote both independence and interdependence. A multi-sensory approach in natural settings and environments is essential for successful achievement of integrated goals and objectives. Experiential learning strategies are employed since many incidental learning experiences are missed by the child who has dual sensory impairments. Opportunities for repetition and practice of skills across a number of daily activities is very important.

Skills targeted in the IEP should be directly observable and measurable with specific criteria for success listed. Adaptations and accommodations are dictated by what the child needs to support participation in his/her program.

Supports (examples) to consider:

- *personal needs (feeding, medical, personal hygiene, dressing)*
- *physical needs (special equipment, environmental modifications)*
- *sensory needs (accommodations for vision and hearing needs)*
- *staff and peer education (how to communicate, what behaviors mean)*
- *provision of access and opportunities (extracurricular activities)*

(Huebner, et. al, 1995, p.117)

Once all the team members present at the meeting have shared information about the current functioning and skills of the child, drafted goals and learning outcomes, agreed upon related services and accommodations to support the child in his/her IEP program, they sign the IEP form indicating their participation in the development process. *(See Mancuso for further details.)*

After the meeting

The IEP is considered a working document. It is to be reviewed annually by the IEP team and changed when needed. Ongoing communication between families and school staff about what and how the child is learning is important.

✎ *This information sheet briefly discusses considerations for IEP development for a child who is deafblind. If you would like more information, you may contact the Pennsylvania Deafblind Project.* ✎

References

Downing, June E., Ph. D. (1996). Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers. Baltimore, MD: Paul H. Brooks Publishing Company.

Huebner, K., Prickett, J.G., & Welch, T.R., Joffee, E. (eds.). (1995) Hand in hand: Essentials of communication and orientation and mobility for your students who are deaf-blind. New York, NY: AFB Press.

Mancuso, E., Rieser, L., & Stotland, J.F. (1991). The right to special education in Pennsylvania: A guide for parents. Philadelphia, PA: The Education Law Center.

It Begins With Communication

Partner agreement

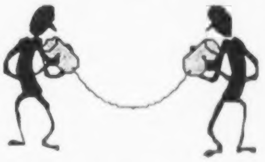
Consistency among partners regarding the occurrence, form, and meaning of communication is the most critical aspect of our roles in helping learners to effectively communicate.

Framework of early communication

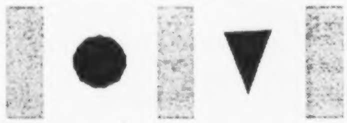
All children communicate in many ways.
Children communicate more competently in familiar and consistent environments.
Responsive and consistent partners enhance children's success.
Contingent responses from the child's world and partner's give him control.
Opportunities to communicate is the foundation for learning.

Communication and language

Communication is the sending and receiving of a message between at least two people.



Language is a system of abstract symbols that is used to communicate a message between at least two people.
You don't need language to communicate.



Symbolic aspects of communication

Nonsymbolic communication includes observable behaviors which partners interpret.
Concrete symbols resemble the item to which they refer, but are not abstract.
Symbolic communication conveys a message with abstract symbols.

Receptive and expressive communication

A partner receives messages via receptive communication.
A partner sends messages via expressive communication.
Partners receive and express messages in multiple forms.

Intentional communication

Preintentional communication may be interpreted in different ways among partners.
Preintentional communication may take the form of accidental or reflexive behaviors.
Partners should share identifications of the form of communication, and the interpretations of the child's communication.
Preintentional communication requires an interactive response from the child's partners.

Partner communication strategies

Look for and respond consistently to all forms of communication.
Consider how current strategies will be used for future programming.
Set up familiar and consistent routines and activities in order to provide many opportunities for learning.
Start out at the child's level of communication so that he is successful.
Use the least amount of prompting when possible.
Use natural reinforces within everyday activities.
Give the learner time to receive information, and time to initiate or respond during interaction.

IEP ideas

Include definitions of the partners' (peers and adults) roles in communication programming.
Spell out sequences, cues, accommodations, and adaptations.
Focus on transition times and familiar activities as the primary setting for

---

Routines and Lesson Plans
Plan before, during, and after activities or events.
Identify opportunities for communication in the plans.
Include descriptions of partners' roles in the plans.

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PA Deafblind Project, Western Instructional Support Center
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Planning The Environment

A child who is deafblind needs extra help in learning about his world. Partners should provide input in a way that can be received by the child. Consistency and familiarity of events and partners provide opportunities for the child to initiate and respond.

Consistency provides a safe and predictable world, with many opportunities to learn.
Be consistent in the:

Method in which you communicate with the child
- *Speech, object cues, coactive signing are examples of methods of communication.*

Sequence
- *Use a touch cue to introduce your presence before each interaction.*
- *Present an object cue (e.g., piece of vinyl from a ball before gym time).*
- *Establish a calendar box that serves as a scheduling device for the day.*

Environment
- *Familiar physical environment allows predictability in the location of items, and permits exploration in a safe manner.*
- *A social environment that includes regular contact with family, friends, and others helps to provide safe and interactive learning opportunities.*

Responsiveness from the environment shows the child that he has an effect upon his world and that he can control his world. Be a responsive partner through:

Contingent responses to the child's communication (even unique and/or preintentional communication)
- *Partners can look for and respond immediately to identified communicative behaviors and purposes.*

Contingent responses from the physical environment
- *Partners can set up activities such as knocking over a tower of blocks.*
- *The child can turn on an adaptive switch-activated toy or appliance.*
- *Effective communication can help the child control their world.*

Source:
Wilcox, M., Baumgarner, J., & Caswell, C. (1990). Young children with disabilities: Facilitating initial communication skills through partner programming. Akron, OH: Children's Hospital Medical Center of Akron.

Other suggested resources:
Goetz, L., Guess, D., Stremel-Campbell, K. (1987). Innovative program design for individuals with dual sensory impairments. Baltimore: Paul H. Brookes.
Siegel-Causey, E., & Guess, D. (1989). Enhancing nonsymbolic communication interactions among learners with severe learners. Baltimore: Paul H. Brookes.

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Information Page

CUES

A purpose of using cues is to help a person understand others' communication through the provision of receptive input. The long-term purpose is to establish a shared message system between the person and other people in his environment, giving the person who is deaf-blind a more effective way to express himself.

- provide information about the environment to a person
- include touch cues, object cues, or gesture cues
- help prevent startling or surprising a person
- can be used receptively and expressively

Suggestions for using cues

- Partners should agree upon a cue and use it consistently in everyday routines or activities in order to provide information for the person.
- Initially, properties of smell, temperature, and texture may be used to increase the amount of sensory input.
- The type of cue selected depends upon what is represented. For example, if an object is not associated with the activity, a touch cue may be selected. If sufficient residual vision is present, a gestural cue may be selected.
- Selection of cues depends upon the person's age, preferences, and opportunities for interaction within his environment.
- To establish an expressive use of the cues, follow a consistent pattern when using the cues. For example, introduce the cue, wait for a consistent and active response (e.g. the person opens his mouth when the cue for "mealtime " is presented), and then respond to the response by performing the action which the cue represents. An additional suggestion is to look for the behavior (e.g., open mouth) to occur at other times, and to respond to that behavior.
- Cues can also be used expressively by an individual through *choice-making* and expression of *preferences* when two or more objects are presented.

Rowlands, C., & Stremel-Campbell, K. (1987). Share and share alike: Conventional gestures to emergent language for learners with sensory impairment. In L. Goetz, D. Guess, and K. Stremel-Campbell (Eds.), Innovative program design for individuals with sensory impairments. Baltimore, MD: Paul H. Brookes.

Watkins, S. (Ed.) (1989) The INSITE model: Home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children. Logan, Utah: HOPE, Inc.

Other suggested resources:

Goetz, L., Guess, D., Stremel-Campbell, D. (1987). Innovative program design for individuals with dual sensory impairments. Baltimore: Paul H. Brookes.

Siegel-Causey, E., & Guess, D. (1989). Enhancing nonsymbolic communication interactions among learners with severe disabilities. Baltimore: Paul H. Brookes.

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Object Cues

Object cues
- provide information about the environment to a person
- can be actual objects mounted on a piece of cardboard or Plexiglass, pieces of an object, associated textures, or miniatures
- help prevent startling or surprising a person

A purpose of using object cues is to help a person understand others' communication. The long-term purpose is to help establish a shared message system between the person and other people in his environment.

Suggestions for using object cues:
- Partners should agree upon a cue and use it consistently in everyday routines or activities in order to provide information for the person.
- Initially, properties of smell, temperature, and texture may be used to increase the amount of sensory input.
- Selection of object cues depends upon the person's age, preferences, and opportunities for interaction within his environment
- While keeping the item as natural as possible, plan ahead as to how the object cue(s) will allow a person to express himself. For example, you may want to plan on mounting the object cues (or a smaller part of the object cue) onto a simple communication board or communication device..

MEANING	OBJECT CUE
Identification of communication partners	Specific to the partner (e.g., ring/hair/watch)
Eat	Spoon
Drink	Cup
Bathroom	Piece of diaper, toilet paper roll
Finished	Bin to put objects in
Bed, sleep	Blanket, small pillow
Play ball	Small ball cut in half
Music	Dial from a radio

Source:

Rowlands, C., & Stremel-Campbell, K. (1987). Share and share alike: Conventional gestures to emergent language for learners with sensory impairment. In L. Goetz, D. Guess, and K. Stremel-Campbell (Eds.), Innovative program design for individuals with sensory impairments. Baltimore, MD: Paul H. Brookes.

Watkins, S. (Ed.) (1989) The INSITE model: Home intervention for infant, toddler, and preschool aged multihandicapped sensory impaired children. Logan, Utah: HOPE, Inc.

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Touch Cues

- are actions or signals performed on a person's body
- let a person know who is with her, and what is about to happen
- help prevent startling or surprising a person
- should be as non-intrusive as possible

A purpose of using touch cues is to help a person understand others' communication. The long-term purpose is to establish a shared message system between the person and other people in his environment.

Suggestions for using touch cues

- Partners should agree upon a cue and use it consistently in order to provide information for the person.
- When selecting touch cues and the way in which the cue will be performed, allow the cue to be nonintrusive and as natural as possible.
- Begin with a small number of cues that represent major activities of the day, and gradually increase the number.
- When you use a touch cue, follow a consistent pattern. For example, perform the touch cue, wait for the person to respond, observe the response, and then provide reinforcement or the action which the cue represents.

MEANING	TOUCH CUE
"Hi" (approach cue)	Lightly rub person's hand
"Bye" (termination cue)	Lightly tap shoulder
"Out/down" (change in placement)	Gently tug arm
"Look/search for"	Shake person's wrist lightly
"Go"	Gently guide elbow
"No"	Tap twice firmly on person's outer wrist
"Finished"	Guide hand to push away object

Source:

Rowlands, C., & Stremel-Campbell, K. (1987). Share and share alike: Conventional gestures to emergent language for learners with sensory impairment. In L. Goetz, D. Guess, and K. Stremel-Campbell (Eds.), Innovative program design for individuals with sensory impairments. Baltimore, MD: Paul H. Brookes.

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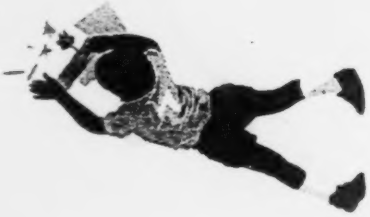
Emergent Literacy



Information Page

Tips for enhancing emergent literacy skills:

Prmote the use of available senses.

Support the use of purposeful movement, and the development of hand and tactile skills.

Link communication skills and goals to literacy goals.

Be sure all children have opportunities to access books and other literacy materials.

Organize and structure the environment to promote active learning.

Involve the student in the full sequence of the activity, with direct hands-on experiences.

Share strategies with the family and other team members.

Introduce experience books, object books, or other appropriate instructional strategies and accommodations.

Accommodate for additional time.

Plan for consistency, repetition, routines, and organization.

From the Quarterly Institute 3: Literacy for Students with Sensory Impairments "Attaching Meaning to Experiences through Literacy" February 17, 1999

A letter from Janna Nelson:

To families, teachers, and students who are deafblind:

Technology has helped me greatly. I use my family's computer for homework. Sometimes there is a required length of time to do something in school, and if I feel I will not be able to tell my interpreter what to write in that time, I may be allowed to do the assignment later on the computer. I may also feel that I do not want my interpreter to know what I want to write; therefore I do the assignment at home on the computer. Sometimes I use the computer for letters, if the recipient does not read braille, or for personal things. This summer, I have been using it to put my journal into it. It will be a long job, but it's worth it.

I use a telebraille to communicate. I have had my grandmother type seminary lessons on the telebraille. Also, if my parents or friends want to talk to me and prefer not to or cannot use sign, they type their messages on the telebraille. I bring the telebraille every time I meet with the Best Friends program so that people can talk to me.

My German teacher also types lessons on it, and her daughter, who is not used to sign, uses the telebraille too. My mother used to take the telebraille to church so that she could type Sunday School lessons and someone else could type Young Women lessons. My mother used to type sacrament meeting also, but she increasingly uses sign. Someone in church used to teach me in a personal class using the telebraille. I did an interview with the bishop on it.

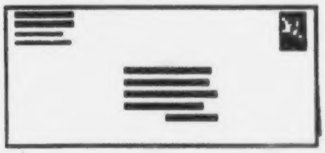
I also type my messages on the computer, and e-mail them from home or school. I also use it occasionally to instruct others to help me use it for such things as trying to locate someone.

If I need or want information, my mother scans it so that I can read it on the computer. The scanner has enabled me to do a few reports. My mother also scanned stories for school, printed them in braille, or left them on the computer for me to read. Once I scanned an entire small book myself with one part needed for a school assignment.

I recently became interested in Switzerland. My mother requested my brother to scan the information about it from the encyclopedia for me to read on the computer.

I have recently received a Braille Lite. I am excited to learn how to use it. It can work with the modem. It can receive files so that I can read them. I can take it along with me to take notes. With a few exceptions, I have to monitor file size, something I don't normally have to do, but it is also smaller and lighter. I can change the file size if I want. This shows how much more comfortable technology is.

Janna Nelson



The other side of the letter...

Janna,19 years old, lives in western Pennsylvania. She has been supported by a community-based transition team, including her school-based educational team. The community transition team was initiated from the State and Local Team Partnership, an effort originally supported by Helen Keller National Center-Technical Assistance Center and the Pennsylvania Deafblind Project. Members of the team include Janna, her family, educators, Blindness and Visual Services counselors, staff from Pittsburgh Vision Services, and others. Membership on the community team has changed, as Janna's needs have changed. The team is currently supporting Janna in her last year of high school.

Technology has been a critical tool in supporting Janna's participation in high school courses, community activities, and other aspects of her life. Adaptations and training have been provided over the years through Pittsburgh School District and Hopewell Area School District to help Janna learn basic computer skills (e.g., key board skills), telecommunications skills (Telebraille, internet), and meeting academic goals (scanning printed materials to convert to braille, taking notes, completing homework). The new Braille Lite is a device for notetaking, and it can be downloaded to a personal computer. Technology is a tool that is used to help Janna meet her current educational goals (including transition) as well as to meet future goals, which include higher education. Janna is constantly learning to adjust to the capacity and functions of her various forms of technology.

If you need information about using technology as a tool to meet educational and transition needs, we may be able to help you by providing information and referrals. Please call the Pennsylvania Deafblind Project.

INFORMATION SHEET

PREFERRED ACTIVITIES AND MOTIVATORS

The following is a summary by Mary Frey of the article, "What Does Amy Like?".

Often it is difficult for parents and teachers of children with sensory and/or multiple disabilities to determine the child's preferences of activities and motivators. In the article, "What does Amy like?" (Fall 1995, Teaching Exceptional Children), the authors, Mason and Egel, suggest a systematic assessment of sensory activities to determine what the child prefers. The goal is to discover a number of sensory reinforcers to use to increase the child's participation in instructional activities.

Examples:

Sarah rocks back and forth in her chair, jumps on the mini-trampoline, dances to the music, and bounces the ball. She appears to enjoy the vestibular stimulation of the activities.

Joey likes to play in water, stand in front of a fan, fingerpaint, use Play Dough and pick up a handful of sand to let it dribble slowly through his fingers. He seems to enjoy the tactile stimulation produced through his behaviors.

Begin by observing and recording what the child does during both free/playtime and instructional time. Note how often, how long, and the context in which the behavior occurs.

Divide the record of behaviors into categories of sensory modalities, focusing on the feedback stimulation produced by a behavior or an object (rocking back and forth = vestibular) rather than on a specific item (swing).

After identifying what sensory modality the child prefers, develop a list of items that represent the preferred activities.

Sample List of Materials for Each Sensory Modality

Visual	*Vestibular*	*Auditory*	*Tactile*	*Thermal*	*Olfactory*	*Gustatory*	*Social*
pocket video games	bouncing a ball	songs	shaking hands	sitting by heaters, air conditioners	scented lotions	food	playing group games
pictures of familiar people	dancing	musical instruments	manipulating textures	ice packs, heating pads	various spices	drinks	fulfillment of requests
kaleidoscopes	roller skating	conversation with others	air from fan/hair dryer	dress up clothes	scratch & sniff stickers		pats on the back
magazines	swimming	radio	"give me five"				providing assistance
mirrors	running	story time	water play				hugs

Organize the items into colo-coded containers holding at least ten different items pre-identified sensory modality:

(1) general storage;
(2) hold items selected that day by student;
(3) hold items not selected.

Perform the Mini-Reinforcer Assessment at least once during the day. By using this process, the child gets to choose new reinforcers each day, tends to get less bored with the stimuli, and increases interest in earning the item for participating in instruction.

Procedures for Adapting a Mini-Reinforcer Assessment

- Placing 10 items for each preferred sensory modality in the storage box.
- When the student arrives at school, sit down with him or her, present two items at a time from the storage box, and say, "Pick one." Wait 10 seconds for a response. If the student reaches for, points to, labels, or looks at one of the items, place it in the "preferred items" box. Place the other item in the "nonpreferred items" box.
- If the student does not respond within 10 seconds, demonstrate the function of both items; remove them for 3 seconds, and present the items again. If the student still does not respond within 10 seconds, put one of the itmes back in the storage box, select another one, and then present the new and remaining items to the student. Wait 10 secondsand, if the student does not respond, put both items into the nonpreferred items box. Continue to present two items at a time, until the student has selected approximately one-half of the available items.
- Place the nonpreferred items and storage boxes out of sight for the day.
- Place the box with the preferred items near your student's work area.
- At the end of each scheduled reinforcement period, give the student one item from the preferred items box.
- Never present the same item two times in a row.
- Allow the student to manipulate the item for 3 to 5 seconds, remove the object, and continue the teaching activity until the next scheduled reinforcement time.

Notes from Mary Frey:
If theobject represents a preferred activity, use your judgement to decide how long the student may engage in that activity until the next teaching activity.

The above article was summarized to give you one suggestion , a beginning point, to determine what is motivating to the student. For more complete information and rationales, read the original article. An article reprint may be obtained by calling Nancy Lehr at the Pennsylvania Deafblind Project to request it.The article is also available from ERIC.

INFORMATION SHEET

Questions and Answers about the Pennsylvania Deafblind Project

Q: What is the Pennsylvania Deafblind Project?
A: The Pennsylvania Deafblind Project (PDBP) is a project that helps professionals and families of children (birth to age 21) who have *both a vision and a hearing loss*. The child may have mild to profound sensory losses and may also have other disabilities. If you are wondering if a child is eligible -- call us!

Q: How can I get more information about "deafblindness" (dual sensory impairments)?
A: PDBP publishes a quarterly Information Update, has a lending library of books and videotapes, produces subject specific Information Sheets, has education and family consultants, and a support staff person. Call us at 1-800-360-7282. If we don't have the answer, we will obtain it through our numerous resources and collaborative relationships. Our offices are located in Gibsonia and Harrisburg but we serve all areas of Pennsylvania.

Q: Can your project help me or refer me to someone who can help?
A: Definitely. Our staff has information regarding agencies who can serve our children with dual sensory impairments. We work in collaboration with a number of education consultants and early intervention service providers across Pennsylvania who deal with children with disabilities.

Q: Can someone come to the child's home or school to help us with ideas?
A: Yes. We have one part time and two full time education consultants and two part time family consultants. All the consultants are available to you by phone (toll free) to brainstorm and share ideas. Depending on the needs addressed, we will travel to any place within the state to provide technical assistance to a child suspected of having combined vision and hearing impairments. At times, we may connect you with other education consultants more local to your area.

Q: I would like to connect with other parents. Can you help?
A: The PDBP's family consultants are each parents of a child with deafblindness. The project has an annual family learning retreat where parents and children from across Pennsylvania meet each other. We host one-day regional learning retreats. The project sponsors study groups with parents. Using Family Learning Awards, the Project provides partial fiscal support for parents to attend relevant conferences. Parents are always welcome to participate in any workshops the Project sponsors. There is a Pennsylvania Parents for Deaf-Blind Group.

Q: Can someone come to the child's I.F.S.P. or I.E.P. meeting?
A: Our consultants will be happy to participate with a child's educational team to assist with planning prior to the I.F.S.P. or I.E.P. meeting. If appropriate, consultants will participate at the actual meeting.

Q: Can I talk with someone about how I am feeling and coping with the child's special needs?
A: Our education consultants are available to listen, to talk and to share strategies for coping. Our family consultants are sensitive to where parents are because they are also parents of a child with deafblindness.

Q: Where will the student go next?
A: Our consultants are available to help you and the child make decisions about the next step in his or her educational or vocational placement. These might include a variety of changes, such as going to a new school, entering college, finding job training, and/or participating in community recreation.

Q: How do I get your assistance?
A: Call us at 1-800-360-7282 and ask to speak to an education consultant of PDBP or to leave a message for a family consultant . All services are confidential and provided only at the request of families, educators or service providers who have children with dual sensory impairments from birth to 21 years of age.

Q: Who pays for the services?
A: All of our services are provided at *no cost* to families, educators and service providers.

Pennsylvania Deafblind Project, 6340 Flank Drive, Suite 600, Harrisburg, Pa 17112-2764
717-541-4968 or toll free in Pa only 800-360-7282

MRF/7-98/educator

REQUEST FOR RESOURCES

INSTRUCTIONS: Please complete the identifying information below, indicate which items you would like to receive, and/or describe your request and someone will contact you for further information. Mail this form to:

Nancy Lehr
PA Deafblind Project
6340 Flank Drive Suite 600
Harrisburg, PA 17112-2764

Name ______________________ Title/Role ______________________

Address ____

Check items you would like to receive:

___*Pennsylvania Deafblind Project Fact Sheet*
___*Family-friendly Deafblind Project Brochure*
___*Questions and Answers about the Project*
___*Considerations in IEP Development for Children who are Deafblind*
___*Preferred Activities and Motivators*
___*Behavioral Issues in Children with Multiple and Sensory Impairments*
___*Tips for Students with Usher Syndrome*
___*A Letter from Janna (about a student's use of technology)*
___*A Story About Alex (about a student's participation in the community)*
___*Surfing the Web*
___*Information for the Audiologist*
___*Information from the Audiologist*
___*Recreation and Leisure (DB-LINK)*
___*Receptive Communication (DB-LINK)*
___*Psychological Evaluation of Children who are Deaf-blind: An Overview with Recommendations for Practice (DB-LINK)*
___*Overview on Deaf-Blindness (DB-LINK)*
___*Early Interactions with Children who are Deaf-Blind (DB-LINK)*
___*Expressive Communication (DB-LINK)*
___*Communication Interactions It Takes Two (DB-LINK)*
Talking the Language of the Hands to the Hands (DB-LINK)

And from various authors
___ *Assessing Young Children with Dual Sensory and Multiple Impairments: Ages Birth to Five Years*
___ *Assessing the School-Age Student with Dual Sensory & Multiple Impairments: Ages 6-15*
___ *Assessing the Transition Needs of Young Adults with Dual Sensory and Multiple Impairments*

Additional/Other Information Needed:
The PA Deafblind Project has many resources which may be helpful to you. Please feel free to call the Project, or describe your needs below:

Juli Baumgarner
Education Consultant

Mary R. Frey
Education Consultant

INFORMATION SHEET

Questions and Answers about the Pennsylvania Deafblind Project

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A: The PDBP's two family consultants are parents. The project has an annual family learning retreat where parents and children from across Pennsylvania can meet each other. We host two one-day regional learning retreats. The project sponsors study groups with parents. Using Family Learning Awards, the Project sometimes is able to provide partial fiscal support for parents to attend relevant conferences. Parents are always welcome to participate in any workshops the Project sponsors. We can forward your name to the Pennsylvania Parents for Deaf-Blind Group.

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A: Our education consultants are available to listen, to talk and to share strategies for coping. Our family consultants are sensitive to where parents are because they are also parents of a child with dual sensory impairments.

Q: Where will my son or daughter go next?
A: Our consultants are available to help you and your child make decisions about the next step in his or her educational or vocational placement. These might include a variety of changes, such as going to a new school, entering college, finding job training, and/or participating in community recreation.

Q: How do I get your assistance?
A: Call us at 1-800-360-7282 and ask to speak to an education consultant of PDBP. You may also leave a message for a family consultant to contact you. All services are confidential and provided only at the request of families, educators or service providers who have children with dual sensory impairments from birth to 21 years of age.

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Pennsylvania Deafblind Project, 6340 Flank Drive, Suite 600, Harrisburg, Pa 17112-2764
717-541-4968 or toll free in Pa only 800-360-7282

MRF/7-98/parents

INFORMATION SHEET

Questions and Answers about the Pennsylvania State and Community Transition Team Partnership for Individuals who are Deafblind

Q: What is the State and Community Transition Team Partnership?

A: The Partnership is an interagency model that utilizes and enhances the existing resources of a community (e.g., local transition teams, area vocational agencies) in planning for a more effective transition to adult life for students who are deafblind.

Q: What types of support exist for Community Teams?

A: A member of the State Team for Individuals who are Deafblind will serve as a liaison to a community team. The state team member can provide training, share successful strategies developed by other community teams, and assist the community team. Additionally, workshop opportunities for all teams occur at least once year.

Q: Who would benefit from this partnership?

A: Students aged 14 years and older with both a visual and hearing impairment, their families, and other members of the transition team would benefit from a focused effort to provide more effective transition services.

Q: What are some of the components of the partnership?

A: The partnership is a person-centered approach that utilizes knowledge of a student's abilities, action planning, and interagency team members' skills in promoting a successful transition process.

Q: What have previous and existing teams learned from participation in this partnership?

A: Teams have learned "process" skills which have assisted in the functioning of effective interagency teams. Examples include: a) setting common **goals**; b) assigning **roles** such as facilitator, timekeeper, and recorder; and c) utilizing an action-planning **process** for transition. Teams also have learned to integrate "content" areas related to deafblindness to the transition planning process. Examples include services which may be needed to support an individual in postsecondary education or work experience. The collective expertise of various teams and team members is also featured in workshops.

Q: Why does this partnership exist?

A: The transition process for the diverse, yet low-incidence, group of students who are deafblind can be complex and challenging. The Helen Keller National Center - Technical Assistance Center (HKNC-TAC), a national technical assistance organization, helped Pennsylvania and other states to establish a partnership between state and community transition teams. This partnership was established in order to develop and enhance effective transition strategies for people who are deafblind, while utilizing existing community resources.

Q: How does this relate to the bigger picture of "transition?"

A: Information from this partnership can be applied to all transition-aged students. For example, many teams report using a person-centered planning approach for all students or clients.

Q: How can I get more information about the State and Community Transition Team Partnership?

A: Contact Mary Frey (800-360-7282) or Juli Baumgarner (800-446-5607, ext. 238) of the Pennsylvania Deafblind Project. You may also ask Juli and Mary to link you with other team members, such as parents.

Pennsylvania Deafblind Project, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764
717-541-4960 or toll free in PA only 800-360-7282

DEAF-BLIND CENSUS OF PENNSYLVANIA

administered by

THE PENNSYLVANIA DEAF-BLIND PROJECT

Your key to technical assistance for children and youth who have both an auditory and a visual impairment

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QUESTION: WHAT IS THE PURPOSE OF THE CENSUS?

ANSWER: Based on the number of children and youth registered, the Pennsylvania Deaf-Blind Project receives funding to provide technical assistance to schools and agencies that provide services for students who have deaf-blindness. Technical assistance is also available for families.

QUESTION: MY STUDENT IS IDENTIFIED AS MULTI-HANDICAPPED. CAN HE/SHE STILL BE ON THE DEAF-BLIND CENSUS?

ANSWER: Yes. You should count students by putting them on all of the census counts for which they qualify, such as: counting them as multi-handicapped on the school count, counting them on the Deaf-Blind Census and on the APH count as a student who is blind.

QUESTION: CAN WE REPORT ONLY ONCE A YEAR?

ANSWER: No. You may update census information whenever changes occur.

QUESTION: WHAT ABOUT CONFIDENTIALITY?

ANSWER: This reporting process completely complies with Federal Reg. 99.31 which permits the disclosure of information about students to state education agencies.

CONFIDENTIALITY

The Pennsylvania Deaf-Blind Project is required under federal regulation (Section 622 of the Education of the Handicapped Act, as amended) to identify children and youth who are deaf-blind in Pennsylvania.

In anticipation of your concern whether disclosure of the information requested without parental consent would violate FERPA, please be assured that the information requested is for the purposes outlined in Reg. 99.31 (ca) (6) and shall be utilized and disposed of as provided therein.

Reg. 99.31 (Prior Consent for Disclosure NOT Required) provides as follows:

(a) An educational agency or institution may disclose personally identifiable information from education records of a student without the written consent of the parent of the student or the eligible student if the disclosure is:

(6) To organizations conducting studies for, or on behalf of, educational agencies or institutions for the purpose of developing, validating, or administering predictive tests, administering student aid programs, and improving instruction, ...[T]he terms [sic] "organizations" includes, but is not limited to, Federal, State, and local agencies, and independent organizations...

WHAT IS THE PENNSYLVANIA DEAF-BLIND PROJECT?

The Pennsylvania Deaf-Blind Project is a federally funded project. Within the State, services are provided for individuals, birth to 21 years with dual-sensory impairments. The project provides technical assistance to families, educational personnel, and other service providers through training efforts and the dissemination of information on innovative approaches to educating children and youth with dual-sensory impairments.

WHO QUALIFIES?

Children and youth from birth to 21 years of age with hearing and vision impairments qualify for services from The Pennsylvania Deaf-Blind Project. Children with deaf-blindness may have concomitant vision and hearing impairments caused by degenerative disorders or central nervous system damage. Children considered functionally deaf-blind:

- may typically have such severe impairment that their visual/auditory acuity cannot be determined by using conventional measures;
- require adaptations in both auditory and visual modes of instruction;
- do not respond to auditory and visual stimuli in their environment.

WHAT SERVICES?

The Pennsylvania Deaf-Blind Project provides assistance to service providers and parents on behalf of children and youth with deaf-blindness (i.e., any dual-sensory impairment). Free services available through The Pennsylvania Deaf-Blind Project include:

- in-service training programs;
- participation in IEP and IFSP meetings;
- consultation regarding teaching strategies and program planning;
- parent to parent contacts;
- information dissemination for both service providers and families; and
- assistance by phone.

Please feel free to call or write us when you are in need of these services!

Mary Frey
PennTech
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
Phone toll free in Pennsylvania (800) 360-7282 or
(717) 541-4960

Juli Baumgarner
Western Instructional Support Center
5347 William Flynn Highway
Gibsonia, PA 15044
Phone toll free in Pennsylvania (800) 446-5607, Ext. 238 or
(412) 443-7821, Ext. 238

DEAF-BLIND CHECKLIST

TO BE CONSIDERED AS DEAF-BLIND FOR THE PURPOSES OF BEING INCLUDED IN THE FEDERAL CENSUS AND RECEIVING SERVICES FROM THE PENNSYLVANIA DEAF-BLIND PROJECT, A CHILD (BIRTH TO 21) WOULD HAVE TO MEET AT LEAST ONE CONDITION IN EACH OF THE FOLLOWING THREE AREAS.

Hearing	Vision	Developmental Concerns
1) Documented auditory handicap meeting Pennsylvania eligibility requirements as cited in State Board of Education Rules or 2) Documented history of chronic otitis media especially during the first six (6) years of life or 3) * Documented hearing impairment (conductive, sensorineural, or mixed) of at least 30 dB in at least one ear or 4) * Documented syndrome/disorder associated with progressive hearing loss or 5) * Diagnosis of auditory processing disorder following testing by a speech-language pathologist, audiologist, and/or psychologist or 6) Caregivers/professionals who know the child and suspect impaired hearing based on: a) significant and otherwise unanticipated delay in receptive and/or expressive speech-language skills or b) responses to the full range of auditory stimuli in the environment is less than anticipated * Examples/definitions on following page.	1) Documented visual handicap meeting Pennsylvania eligibility requirements as cited in State Board of Education Rules or 2) * Documented syndrome/disorder (including genetic) associated with loss of vision or 3) * Documented syndrome/disorder associated with progressive or fluctuating vision loss or 4) * Diagnosis of cortical visual impairment from ophthalmologist and/or neurologist or 5) * Diagnosis of nystagmus or 6) * Diagnosis of amblyopia after the age of six years or 7) * History of untreated eye condition, such as cataracts, any time during the first three (3) years of life or 8) Documented visual impairment of 20/70 or worse after correction in better eye or a loss in visual field or 9) Caregivers/professionals who know the child suspect visual impairments based on: a) visual attending and/or visual examining behaviors are less than anticipated or b) * impaired visual-motor functioning, resulting from strabismus or cerebral palsy or 10) * Visual perception problems	1) At least one year delay on developmental assessments or one standard deviation from score expected on the basis of chronological age on standardized assessments in one or more of the following areas: a) communication skills (including speech and language) b) social skills c) spatial awareness and orientation d) basic concepts e) academic achievement f) visual and/or auditory guided movement g) self-help skills or 2) At risk for problems with independent living and/or competitive employment upon graduation from high school or 3) At risk for problems with integration into family life/community activities or 4) At risk of getting hurt when walking/moving around independently or 5) Under the age of five (5) years

Suggested uses for this Checklist:
(1) To evaluate each of the students in special education.
(2) To present to parents as a tool to help develop an understanding of their child's needs for program modification because of sensory deficits.
(3) To keep in child's records.

* EXAMPLES

Hearing

3) * A conductive hearing loss is caused by problems in the outer ear or middle ear; e.g., blockage of the ear canal, damage to the ear drum, problems with the bones in the middle ear, fluid in the middle ear.

A sensorineural hearing loss is caused by nerve damage to the inner ear.

A mixed hearing loss is a combination of conductive and sensorineural impairments.

4) * Some examples of syndromes associated with progressive hearing loss include:
   - * Norrie Syndrome
   - * Sticklers Syndrome
   - * Kniest Syndrome
   - * Goldinhar Syndrome
   - * Mohr Syndrome
   - * Paget Syndrome
   - * Cockayne Syndrome
   - * Hurler Syndrome

5) * Reports from professionals that may include such terms or descriptions as:
   - * central auditory processing problem
   - * central auditory processing dysfunction
   - * difficulty in understanding what is heard

Vision

2) * Some examples of syndromes or disorders associated with loss of vision include:
   - * Congenital cataracts
   - * Retinopathy of Prematurity
   - * Retinal Blastomas
   - * Noonan Syndrome
   - * Morquio Syndrome
   - * Marfan Syndrome

3) * Some examples of disorders associated with progressive or fluctuating vision loss include:
   - * Retinitis Pigmentosa
   - * Usher Syndrome
   - * Glaucoma

4) * Cortical visual impairment results in the inability of an individual to process visual information.

5) * Nystagmus is an involuntary rapid movement of the eye.

6) * Amblyopia is uncorrectable blurred vision due to disuse of the eye.

7) * Cataracts are a clouding of the lens of the eye.

9b) * Strabismus is a deviation of the eyes so they are not simultaneously directed to the same object.

10) * Examples of visual perception problems:
   - * Child may be observed to overreach or underreach for objects.
   - * Child may misjudge where the food is on a plate.
   - * Child may be confused by color or texture of walking surface.

A Story about . . .
Alex

Spring 1997

Dear All,

Hello, my name is Alex. I am six years old, and I love my family. I have Cornelia deLange Syndrome. CdLS has affected my heart, ears, eyes, and growth. I have survived heart and glaucoma surgery, and I wear contact lenses. I used to wear hearing aids, and I am going to start wearing them again. Since I was born, I have learned very much. My family and my teachers have helped me learn how to sit and walk, and I can find my classroom all by myself. I had a hard time learning to eat, but now I can eat anything!! I have a lot to say, so now I am learning to use simple pictures, switch-activated taped messages, manual signs, and objects to express myself. I understand much more than I can say. That's pretty tough sometimes, for me AND my family, because they want to know what I would like and how I feel.

I have an older sister and a little one, too. They're really nice. Sometimes I "bug" them, but sometimes they bug me too. Mom and Dad want me to do the same things as my sisters, so last summer I went to Vacation Bible School. I had a great time learning and playing with the other children. They liked me. We took turns on the sliding board. They asked me why I don't speak words, but that didn't stop them from playing with me! I'm going back to Vacation Bible School this summer.

Because I have problems seeing and hearing and because sometimes I get bored when I'm not sure how to play with some toys, I have learned to provide myself with other sensory input. Some of the input that I give to myself makes it harder for me to learn to play and communicate. So now I am learning to use my hands just like other little boys do.

My family has tried to make sure that I am always learning. I have gone to different schools. Now we are talking to the school in my neighborhood, and we are planning for me to attend that school. I won't need to be on the bus for so long, and I will be learning to communicate and play with the kids who live by me.

Sincerely,

Alex

THE REST OF THE STORY . . .

Alex's mother, Molly, has attended several workshops given by the Pennsylvania Deafblind Project, as well as other workshops in Pennsylvania and nationally. She states that the information from workshops, conferences, and other resources allow her family to gather perspectives from many views, and sift through ideas that can apply to Alex. Molly makes an important point that the views and goals for a child may be different. They can vary at different points in time, or due to different priorities, such as one person focusing on a child learning to walk, while the other person is focused on the child's communication.

Our life experiences (e.g., father, teacher, sister, doctor) also color our views of the child. We need to come together and sew our visions and dreams into one quilt for the child so that we are not scattering our efforts in isolation. The quilt can be washed, mended, and added to over time. Yet we must keep one picture of the whole child, not splintered pieces that do not interrelate.

Gather information and support, bring it together; and remember to review it, like going back to a favorite photo album. Enlist others as a team in integrating your goals for your child. If the team needs assistance, the Pennsylvania Deafblind Project can explore options with team members. Many unfinished craft projects can help us attest to the fact that it is much easier for a group of people to accomplish a goal than for one person to work alone.

Seek out information, such as written materials or videotapes. Molly is part of a study group of parents and one teacher who review self-study materials on deafblindness and then discuss via phone conference calls how the information they have learned applies to their children. The Pennsylvania Deafblind Project supports this activity by providing materials, assistance, and sponsoring the phone calls.

If you have a story to share or would like some help, contact us at:

PENNSYLVANIA DEAFBLIND PROJECT
6340 FLANK DRIVE, SUITE 600
HARRISBURG PA 17112-2764
Phone: 800-360-7282 (in PA only)
or 717-541-4960
e-mail: http://www.cisc.k12.pa.us

A STORY ABOUT ZENOLA

by Juli Baumgarner, PA Deafblind Project

"A Story about Zenola" is based on an original interview conducted by Wayne Kotanko, who is a friend and support to Zenola Tyson. Much appreciation is extended to Mr. Kotanko for sharing his interview, and to Zenola for sharing her story.

Zenola is a wife, mother, and employee. She is a leader in the Deafblind community in central Pennsylvania, and is active in the Central Pennsylvania Association of the Deaf-Blind. Zenola has Usher Syndrome, which affects both vision and hearing.

Zenola's parents found out that she was deaf when she was one year old. They noticed that she did not react to a loud fire alarm, and took her to see a specialist, who informed the family that Zenola had been deaf since birth. The rest of her family, including two brothers and a sister, are hearing. She did not have much exposure to other children who were deaf when she was very young, but subsequently attended a school for the Deaf. Her loss of vision due to retinitis pigmentosa was not identified while she attended school. Unknown to Zenola, she was gradually losing her peripheral (also called "tunnel vision") and night vision. The other students felt that she was ignoring them, when in fact she couldn't see them gesturing, signing, and waving to her.

After Zenola finished school, she became married and employed. She knew there was something happening with her vision and her husband encouraged her to see a doctor. A specialist informed Zenola that she had Usher Syndrome. Usher Syndrome is a combination of deafness or hearing loss, along with gradual loss of vision due to retinitis pigmentosa.

This diagnosis was a shock to Zenola and everyone in her life. They felt a range of emotions such as denial, anger, and disbelief. Zenola had to deal with the diagnosis and the impact that it had on those around her. With the support of friends and a loving family, especially her husband and son, she made her way through this difficult process.

Even though Zenola had strong skills in American Sign Language due to her education at a school for the Deaf, she noticed that her interactions with people from the Deaf community changed. As her vision changed, she reported that she had to wait for someone to come up and start talking to her, limiting her conversation with others. It can be a tremendous challenge for others to accept and understand how the eye condition of retinitis pigmentosa intensely affects the visual aspect of sign language, which is relied upon by the deaf community.

She had to learn to use tactile signing, which is a method of communication that involves putting one's hands on the interpreter's hands to follow the interpreter's signs. For four and one-half months, she concentrated on learning to use tactile sign (When you meet her, her name sign is "ZT"). Zenola had to learn many new skills, such as how to handle a guide dog, and to manage household chores. She attended the Helen Keller National Center in New York to continue her education on these new skills. When she returned home, she taught her husband and son what she had learned.

Through learning new skills and information, Zenola is now able to cope with deafblindness due to Usher Syndrome. She enjoys her employment as a production worker and packer, and also her hobbies of reading and history. She leads a very active life, and helps others through her involvement in the deafblind community. She has been the president of the Central Pennsylvania Association of the Deaf-Blind for four years, and is a support and mentor to others. She is a board member of the PA Statewide Independent Living Council. Her son is 20 years old, and she is married to her "hubby" James, who has been with her through the years! She will soon be a grandmother.

If you would like to get in touch with Zenola, or for more information, please call the PA Deafblind Project.

More about this story....

What is Usher Syndrome?

Usher Syndrome is a major cause of deafblindness in adults. There are three types of Usher Syndrome, but all are combinations of deafness or hearing loss along with retinitis pigmentosa (tunnel vision), a decrease in night vision, and sometimes balance problems. Usher Syndrome may occur when both parents carry the gene. It is recessive and autosomal, so both parents may carry the gene, but there is a one in four chance that their child would be born with Usher Syndrome. Often, parents are unaware that they carry the gene.

Statistically, three to six percent of students who are deaf or hard of hearing have Usher Syndrome. Currently in PA that would be equal to 84 to 168 students, but only eleven students in PA have been identified as having Usher Syndrome. This is a significant under-identification of students, if compared with the estimated numbers.

Why is Usher Syndrome Under Identified?

There are a variety of reasons. Screening for vision problems either may not occur, or may occur but not include screening for RP. Many people are unaware of Usher Syndrome. Teachers and families are aware of a potential problem, but delay actual identification and discussion of Usher Syndrome, because of the enormous implications on issues such as independence, communication, membership in Deaf culture that relies on a visual language, and the impact of deteriorating vision. Only a medical expert can diagnose Usher Syndrome, but the observations of the student, teachers, and family are invaluable in realizing the need for the diagnosis.

What can we do?

Educators and families can be trained to look for signs of possible vision problems. Signs of possible vision problems include problems adjusting when going from darkened to lit areas, or vice versa (e.g., leaving an auditorium, going outside at night). Also, some students with Usher Syndrome experience balance problems (e.g., problems on a bicycle). Students may appear to be clumsy (e.g., tripping over curbs, having trouble walking around furniture) because their visual fields are restricted. Students may have trouble seeing items of low contrast, such as poor quality photocopies. Squinting because of a sensitivity to glare, and reduced acuity may also occur. Please note that these are only a few examples of potential signs of vision problems, and that assistance is available from the PA Deafblind Project and your local vision professionals.

Periodic vision screenings for all children should include a screening for fields of vision. Vision screenings for children who are deaf or hard of hearing should include a screening for RP. A significant number of students who are deaf or hard of hearing experience vision problems which, if not addressed, would significantly affect the educational process, including visually based sign language and/or lip reading.

Support is needed for the family, student, and other members of the team if the screening process indicates a potential vision problem. Medical practitioners and the educational team must work together in identifying and addressing the educational needs of students. Students who are experiencing vision loss, and the people in their life may need help in adjusting and adapting to changes. Young adults with Usher Syndrome ask that we identify and address these issues in age-appropriate ways as soon as possible. Early identification ensures that necessary skills such as braille and orientation and mobility are learned in a timely manner. The need for support, role models, and counseling can also be identified as soon as possible.

For more information, please contact the PA Deafblind Project. Here are some current resources:

Information Sheet: Tips for Students with Usher Syndrome (1998). Baumgarner, J. PA Deafblind Project. Available from PA Deafblind Project or www.cisc.pa.k12.us.

When Hearing Loss and Retinitis Pigmentosa Happen Together: Meeting Educational Needs. (March 5, 1996). A video teleconference from the Distance Learning Center (DLC) of Pennsylvania. Available from the DLC (724-443-7821) for purchase; or on loan from the PA Deafblind Project.

Usher Syndrome in the School Setting (1997). Miner, I., & Cioffi, J. Helen Keller National Center: Sands Point: NY. Available on loan from PA Deafblind Project.

JB 5/98

INFORMATION SHEET

SURFING THE WEB . . . Ten Easy Steps

Are you brand new to the World Wide Web? If you can access a computer that is hooked up to the Internet, follow the steps below and you will be surfing in no time!

1 Ask someone which "browser" the computer has. The"browser" is the type of software the computer uses to access the World Wide Web (WWW). The most common browsers are Netscape Navigator, Microsoft Internet Explorer, and AOL (America Online). Accessing the WWW through AOL is a little different, so you will need to have someone who knows how to use AOL to help you start.

2 Using the computer mouse, point to the name of the browser on the computer screen with the little picture attached (known as "icons"). The browser will start up, and you will see a Web page.

3 The Web page that is now in the window is the browser's "home page." Notice that toward the top of the screen, there is a button called "Home." Every time you point and click on that button, you will return to the page that is now displayed. You can go anywhere on the WWW using the buttons you now see on the browser.

4 In both Netscape and Internet Explorer (IE), you will see a bar near the top of the window where a "Web address" is shown. A Web address looks something like this: http://www.cec.sped.org (CEC's Web address). To go to a different Web page, double-click on this box. When the address is highlighted, you can type over the old address with a new address (try the CEC Web address above) and press "Enter" on the keyboard. You can also go to a Web page by clicking once on the "Open" button in Netscape, then type in the address, then click on "open." The browser will locate that page on the WWW.

5 To move from Web page to Web page (known as "surfing"), click on text on the page that is a different color than the rest of the text (it is also often underlined as well). If you typed in the CEC Web address, you will see a picture and the word "Continue." There is no other text on this page, but "Continue" is colored text, and it is underlined. Point to it. Notice that you mouse pointer turns into a little hand. This text is known as a "link," because if you click on it you will be taken to another Web page. Click on "Continue."

6 Images can be "links" as well. An image is a link if your pointer turns into a hand when you point at it on the screen. The CEC home page you are now on is an image with lots of different areas to click. Point to the area of the image that lists information you are interested in. Now click again!

7 Now you are on a different Web page. If you wish to go back to the CEC home page, you can point and click on the "Back" button in your browser (top of page). When you click on "Back," you will be taken to the previous page you viewed (you can do this many times, and you will keep going to each page you viewed since you opened the browser). Click the "Back" button.

8 You can also move to different pages using the "Forward" button at the top of the browser. This will take you forward to the page you were just viewing.

9 It is very important for Web surfers to be able to return to their favorite Web sites without having to remember all of those crazy Web addresses. Browsers make this easy to do. When you are viewing a page that you may wish to return to in the future, do the following:

Find the word "Bookmarks" or "Favorites" at the top of the screen and click on it, keep pressing on the mouse button, and pull the mouse toward you until the words "Add Bookmark" or "Add to Favorites" are highlighted. Now release the mouse button. When you click and hold your pointer on "Bookmarks" again, the name of the page will be listed. The browser will keep that name on the list. To return to that page, click and hold your pointer on "Bookmarks" or "Favorites," and pull the mouse toward you until the name of the Web page you want is highlighted, then release the mouse button. You have now selected that Web page location , and the browser will take you to that Web page.

10 These are the basic ways to begin surfing the Web. Of course, there are other things a browser can do, and there are lots of ways to search for information, but **congratulations!** You **are now surfing the Web!!**

From CEC, Vol. 4 No. 2, August 1997

SURFIN' THE WWW WITH JEAN

It all started about two years ago when we were given a "name" to Rebecca's "problems". We had been told she was deaf, and had Retinitis Pigmentosa, which meant she couldn't see very well, and it would progressively get worse. She would eventually become totally blind. Why?

Then one day at Childrens' Hospital in Pittsburgh, a doctor came across a blood work-up that got us started on a trek to Johns Hopkins in Baltimore, Maryland, where we were told that her diagnosis was Infantile Refsum's Disease (IRD). What was this? Well, we were given some information to read, which really scared us. IRD is under an umbrella term called Adrenolukodystrophy. When we investigated this, we got even more scared. We said this can't be Becky, she doesn't fit these characteristics. But life went on, and we endured, and tried to educate ourselves, with very little to go on

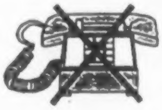
Earlier this year, I had the honor, and pleasure of going to the National Deaf-Blind Conference in Washington, D.C. The first day there, the parents were required to attend a "get acquainted" meeting. Each parent stood up and told who they were, where they were from, and a little about their child(ren)with deafblindness. As we went around the room, a man stood up and said he also has a son that is IRD. He was from the state of Washington. This really startled me. We hooked up immediately, and started comparing notes. He had so many more notes than I did!!! We found many similarities between our children. He also told me about how there are very few of us in the world, and it would be better odds at winning the lottery than having a child with IRD. We shared pictures, etc. He also told me about the Internet connection he and his wife had made with a lot of the IRD, families, and doctors.

When we were wrapping up our sessions on the last morning, we were asked to write down our immediate goals for when we came home. I can actually say that I have achieved one of my goals!! I investigated getting on the Internet. My computer buddy came over and looked at my computer, told me it was ancient and I needed to upgrade. This would normally be a big financial problem; however, we had just sold our old home, and I had a little "spare change" laying around, so we made the investment.

My friend in Washington then introduced me to a LISTSERV for the deafblind. There are all kinds of different situations on this listserv, from all over the world. I have communicated with Sweden, Germany, England, Canada, South America, even Australia. I have met Usher's Syndromes, Charge Syndromes, and many are parents of a child who is deafblind, regardless of the child's age. They discuss everything, from IEP preparation to government legislation. I have really enjoyed this listserv. Even though I am very new to this field, and haven't communicated very much, I have enjoyed reading and learning from their experiences.

So, what have we gained by using the internet? Well, we have met other deafblind, both young and old. We are able to communicate with other families with the same syndrome as Becky (there are less than 100 in the world and none within this state that we know of). We can communicate with her doctor at the Kennedy Krieger Institute (Johns Hopkins) without having to disturb him at work. We can think about our questions, and he can think seriously about his answers without being required to respond immediately. We don't have to play phone tag. I can learn from others' experiences as well as look for advice. (It beats Ann Landers, as I usually get a response within about 4 days.)

The Internet service is costing me about $20.00 a month, and considering the different places I am communicating, Ma Bell would own me if I was doing this on the telephone. The "subscription" to the listservs is free, regardless of how many you use.



I am learning there are many other listservs out there. The DB LINK is accessible through the Internet, the Helen Keller Association is there, and many, many different medical areas. There are even advertisements for various areas of employment within the deafblind field

To subscribe to the deafblind listserv, send the following in the body of an e-mail message (note that "deafblnd" is the correct spelling): SUBSCRIBE DEAFBLND firstname lastname. Send to listserv@tr.wou.edu. Good luck with your surfin', and I'll see you on the 'net!!!!

Jean Weaver
jrweaver@sgi.net

WWW

✎ INFORMATION SHEET ✎

Tips for Students With Usher Syndrome

by Juli Baumgarner, Education Consultant, Pennsylvania Deafblind Project

CLASSROOM ACCOMMODATIONS AND ADAPTATIONS

Lighting:

- ✓ Lighting should be adequate without glare. Use full spectrum lighting whenever possible.

Seating:

- ✓ Teachers should provide group instruction from a non-cluttered background area, and avoid unneeded movement.
- ✓ Windows should be behind students. Teacher should never be in front of windows.
- ✓ Furniture should be arranged to provide easy movement in open space. Keep drawers and doors closed. Discuss all furniture rearrangement with students. Seat students where they are comfortable (e.g., possibly front side so they can see the chalkboard and other students in the class).

Classroom Environment:

- ✓ Chalkboard should be cleared of unneeded marks, and regular printing (instead of all capital letters) used. Use white chalk only.
- ✓ Colors should be softly neutral, yet textured, in the background of the teaching area. Floors and carpets should not be dark red or brown.

MATERIALS

Learning Media:

- ✓ Conduct a learning media assessment to determine appropriate learning media and strategies.
- ✓ Print should be maximum contrast. Avoid dittos; if dittos must be used, give the student a yellow acetate overlay to use.
- ✓ Use non-glare paper, and evaluate the size of type which is most appropriate for individual students.
- ✓ Develop the use of tactile skills as early as possible.

Individualized classroom materials and procedures:

- ✓ Students may need individual copies of wall-hung graphs or charts, or they may need time to examine these charts close-up.
- ✓ Tests may have to be adapted for individual use, including allowing students to mark answers on test booklets or providing the test in a different format.

Assistive technology:

- ✓ Low-vision aids may eventually be prescribed, and assistive listening devices can be used.

TECHNIQUES

Sign language:

- ✓ Others may have to adapt their sign language to adjust to the student's limited vision. Keep signs as small and concise as possible, and increase the duration of each sign. Eventually, tactile sign may be an option.
- ✓ Interpreting services may be necessary to allow access to instruction and interaction. Evaluate the need for these services on a regular basis, to ensure that the student is aware of what is happening around him or her.
- ✓ Begin including more and more tactile and olfactory materials and cues for the student. A vision teacher and/or an orientation and mobility specialist can recommend techniques to use during specific activities.

Orientation and mobility:

- ✓ Document the assessment and support needs for the student to travel independently.
- ✓ Explore the use of sighted guide, self-protective techniques and trailing skills, and land marking skills and techniques.

Time allowances:

- ✓ For all tasks, students may need "time and a half" to complete the same work as their peers. When doing repetitive academic work, students can be assigned half the questions or problems their peers are assigned to equalize the length of time spent in homework or academic drill.

SELF ADVOCACY

Adaptations and accommodations:

- ✓ Assist the student in developing strategies to discuss necessary adaptations and accommodations, or to communicate other needs.

Independence:

- ✓ Encourage the student and family to link with others for support and networking.

References

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Torres, I. & Corn, A.L. (1993). When you have a visually handicapped child in your classroom: Suggestions for teachers. New York: American Foundation for the Blind.

PA ANNUAL DEAFBLIND CENSUS 1996-1997

If you need an evaluation of a student's vision.....

Promoting the most effective use of a student's vision will give him/her optimal chances for learning. Evaluation of how a student uses vision includes observation by the family, classroom or itinerant teachers, evaluation by a teacher of those with visual impairments, and an eye specialist such as an ophthalmologist.

If you are having difficulty in obtaining specific information about a student's vision, here are three suggestions.

1) Complete the "Vision Questionnaire" (attached). Make sure that all the members of the student's team, including parents, have input in answering the questions.

2) When observing the student's use of vision, look for patterns. Write down the circumstances, describe the environment, and list the observed behaviors.

3) Make an appointment for an evaluation of the student's vision. A vision consultant or a teacher of the blind or visually impaired at the local intermediate unit, school district or early intervention agency should be able to suggest several resources for the evaluation. Provide the information from the "Vision Questionnaire" and other documented observations by team members with the eye specialist who will be doing the actual vision evaluation.

Use the information obtained from the questionnaire and evaluation to determine how best to provide information and instructional materials to the student.

If you need further assistance regarding a referral for testing a student's vision or in completing the census form, contact Mary Frey at the PA Deafblind Project at 800-360-7282 (extension 3005).

• For the purpose of completing the Annual Federal Census for the Deafblind conducted by the PA Deafblind Project, use the vision evaluation results to determine the most accurate response. Located on page 2, question #2 of the census form, mark the degree of vision in the better eye with correction in response to:

3. What is the degree of vision loss?
   - ___ Partially sighted (20/70 - 20/200)
   - ___ Legally blind (less than 20/200 or visual field of less than 20 degrees)
   - ___ Light perception only
   - ___ Totally blind
   - ___ Tested - Results nonconclusive - Comments (need to tell why)
   - ___ Not tested - Reason (need to explain why and when plan to test)

Reference

Flexer, C., Baumgarner, J. & Wilcox, M.J. (Ed.). (1989). Children with dual sensory impairments series: Guidelines for determining functional vision in school-based settings. (Available from Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278).

MRF & JB/1-97/census

VISION QUESTIONNAIRE

Name of Child/Student: ____________________ DOB: __________

Person Completing Form: ____________________ Date: __________

Do you believe that the child has any difficulty seeing? yes_____ no_____
If yes, please explain:

____

____

Has the child ever been suspected of having vision problems? yes_____ no_____
If yes, please explain:

____

____

____

Has the child ever had a vision exam? yes_____ no_____ date of last exam: __________
If yes:

Who did the exam? ____________________

What, if anything, was prescribed or recommended (glasses, medication, surgery)?

____

Were the results of the exam explained to you? yes_____ no_____

Do you have a copy of the report? yes_____ no_____

Please briefly describe the results (or attach report): ____________________

____

Does the child wear glasses? yes_____ no_____ used to but does not now _____

If glasses have been prescribed at any time, please describe why the child does not currently wear the lenses (for example, no longer necessary, won't keep them on).

____

____

Reference

Flexer, C., Baumgarner, J. & Wilcox, M.J. (Ed.). (1989). Children with dual sensory impairments series: Guidelines for determining functional vision in school-based settings. (Available from Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278).

Does the child look at objects with the eyes? yes________ no________

If yes, please describe the types of objects, what size? Does s/he follow objects only of certain colors, shapes, or sizes? Do the objects have to be a certain distance (like very close) for the child to be able to follow them? Do the objects have to be moving? Can they be still?

____

____

Does the child follow the movement or path of objects with the eyes? yes_______ no_______

Up/Down: yes_______ no_______ Right/Left: yes_____ no_____

Randomly? yes_____ no_____ Follows only certain objects? yes____ no____

Does the child use both eyes together to look? yes_____ no______

Do one (or both) eyes turn inward (toward the nose)? no_____ always_____(right/left/both)

Sometimes? yes______ no______(right/left/both)

Do one (or both) eyes turn outward (away from the nose)? no____ always____(right/left/both)

Sometimes? yes______ no______(right/left/both)

Does the child have any difficulty getting around a room, the house/school? yes_____ no______
If yes, please explain:

____

How does the child explore unfamiliar objects (puts in mouth, holds up to eyes, touches and feels, listens, looks, etc.)?

____

____

If the child looks at objects, does s/he hold the objects close to the face, and/or hold them at a specific angle?

yes________ no____________

If yes, please explain: ____

____

Does the child do unusual things like watching his/her hands, poking the eyes, staring at lights?

yes________ no___________

If yes, please explain, noting how often these behaviors occur: ______________________

____

PA ANNUAL DEAFBLIND CENSUS 1996-1997

If you need an evaluation of a student's hearing.....

As educators and families, we need to know how a student can best use his/her hearing in order to learn. Testing a student's hearing involves using an array of observational, behavioral, educational, and medical testing. Families, classroom or itinerant teachers, teachers of the deaf or hard-of-hearing, audiologists, and otolaryngolists (ear-nose-throat doctors) are all people who together can provide information about how a student uses his/her hearing.

If you are having difficulty in obtaining specific information about a student's hearing, here are three suggestions.

1) Complete the "Observable Auditory Behaviors Questionnaire" (on the reverse of this page). Make sure that all the members of the student's team, including parents, have input with answering the questions. Be aware that people may answer the same questions differently depending on the environment or situation. Look for common trends in responses to provide information about the student's hearing.

2) Complete the attached "Information for the Audiologist" form. This information will be very useful to the audiologist who will be doing the actual hearing evaluation.

3) Make an appointment for an audiological evaluation of the student's hearing. A hearing consultant or a teacher of the deaf or hard-of-hearing at the local intermediate unit, school district, or early intervention agency should be able to suggest several resources for the evaluation.

Use the information obtained from the questionnaire and evaluation to determine how best to provide information and instruction to the student.

If you need further assistance regarding a referral for testing a student's hearing or in completing the census form, contact Mary Frey at the PA Deafblind Project at 800-360-7282 (extension 3005).

• For the purpose of completing the Annual Federal Census for the Deafblind conducted by the PA Deafblind Project, use the audiological evaluation to determine the most accurate response. Located on page 2, question #3 of the census form, mark the Pure Tone Average for the better ear in response to:

3. What is the degree of hearing loss?

___ Mild (30 - 45 db loss)
___ Moderate (46 - 70 db loss)
___ Severe (71 - 90 db loss)
___ Profound (91+ db loss)
___ Tested - Results nonconclusive - Comments (need to tell why)
___ Not tested - Reason (need to explain why and when plan to test)

Reference

Flexer, C., Baumgarner, J. & Wilcox, M.J. (Ed.). (1990). Children with dual sensory impairments series: Guidelines for determining functional hearing in school-based settings (Available from Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278).

MRF & JB/1-97/census

BEST COPY AVAILABLE

OBSERVABLE AUDITORY BEHAVIORS QUESTIONNAIRE

Attentive Type Behaviors (these often suggest learning)

	✔ all the time	✔ most of the time	✔ some times	✔ seldom/ never
1. If sleeping, does the child awaken to sudden noises?				
2. Is the child soothed by mother's or caregiver's voice?				
3. Is eye widening, a type of "what is it?" response, observed?				
4. Are the eyes observed to search for the sound?				
5. Do the eyes appear to directly localize the sound?				
6. Does the child exhibit head searching and perhaps a rudimentary head turn toward the sound?				
7. Does the child turn head toward the side the sound is presented?				
8. Does the child localize the sound directly when presented to the side, below, and above?				

Reflexive Behaviors (these behaviors are at the level of the brainstem)

	✔ all the time	✔ most of the time	✔ some times	✔ seldom/ never
1. Does the child startle when sound is presented in a quiet room?				
2. Do the child's limbs move involuntarily when sound is presented?				
3. Do the child's eyes blink when sound is presented in a quiet environment?				
4. Does the child start or stop sucking when sound is presented?				
5. Does the child's breathing rate change when sound is presented?				
6. Are facial twitches noted when sound is presented?				
7. Are arousal and quieting observed as a reflexive or an attentive behavior?				
8. Does the child start or stop crying to loud sounds?				

NOTE: Even if a child initially responds to sound with reflexive behaviors, he or she deserves an opportunity to learn to respond more meaningfully. Current function does not always predict future potential.

Adapted from: "List of Auditory Behaviors that can be Observed in Hearing Testing and in the Classroom" Appendix D in Flexer, C., Baumgarner, J. & Wilcox, M.J. (Ed.) (1990). Children with dual sensory impairments series. Guidelines for determining functional hearing in school-based settings. (Available from Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278).

INFORMATION FOR THE AUDIOLOGIST

The following guideline will assist the audiologist in obtaining the best evaluation possible for the child. Parents, teachers, speech-language pathologists, and other individuals who are very familiar with the child can complete this form. This information would be most effective if it were sent to the audiologist before the child's appointment.

DATE ____________________

To whom it may concern:

________________________ has an appointment for an audiological evaluation at your facility on ____________
__________________.

We hope that the following information is useful to you. Please call us if you have any questions.

Parent or guardian ______________________________________ Phone______________________________

Teacher/other ____Phone ______________________________

Do I think this child can hear? ____

Results of previous behavioral testing: ____

Results of previous auditory brainstem response (ABR) testing: ____

Results of previous immittance or impedance testing: ____

Suspected causes of hearing loss (e.g., specific diagnosis, history of chronic middle ear infections, excessive earwax): ____

COMMUNICATION LEVEL OF STUDENT:

______ Does not appear to understand spoken directions, but does follow directions if given gestures

______ Expresses needs mostly with gestures and sounds.

______ Expresses needs with ten or fewer single symbols (words, signs, symbols on a communication board).

______ Usually expresses needs with symbols (words, signs, symbols on a communication board).

______ It is usually not possible to understand child's communication.

Simple one-word commands and object/person names that the student understands (e.g., waves "bye", points to body parts, understands name): ____

Student _____ does/ ______ does not imitate sounds. If yes, what type of sounds? (e.g., car sound, animal sounds, speech sounds, words): ____

MOTOR ABILITIES:

The following movements are used voluntarily (e.g., turn head, reach, reach and push, point, eye movement)

____

VISUAL ABILITY:

______ Light/dark perception

______ Can see only in some visual fields

______ Sees better when items are very near

______ Sees better when items are far away

______ Can see near and far in all visual fields

AUDITORY BEHAVIORAL RESPONSES:

The following is a checklist of auditory behaviors which have been observed at home or in the classroom:

A. Behaviors observed when sound is presented in a quiet room:

______ Startles
______ Blinks
______ Involuntary movement of arms and/or legs
______ Other (please describe)________________
____

B. Behaviors observed when sound is presented:

______ Change in breathing rate
______ Searches for sound with eyes
______ Facial twitches
______ Arouses
______ Quiets
______ Starts or stops crying to loud sounds
______ Other (please describe)
____
______ Is soothed by mother's or caregiver's voice
______ If sleeping, awakens to sudden noises
______ Eyes appear to directly localize to sound
______ Head movement as a search for sound
______ Head turn toward the sound
______ Eye widening occurs
______ Head movement toward sound when presented from different directions

Child is most responsive to the following sounds: ________________

The following are voluntary or involuntary consistent responses to sound: ________________
____

Does child tolerate earphones? ______ yes ______ no

Has the child resisted previous audiological testing? ______ yes ______ no

If yes, how can this be avoided? (e.g., audiologist should not wear a white lab coat): ________________
____

Does child respond better to a quiet and subdued style of interaction, or to an animated style of interaction?
____

List all amplification devices (e.g., hearing aid, auditory trainer) formerly or currently used): ________________
____

How does child respond to the devices? (e.g., resists, is indifferent, cries): ________________
____

Appendix C in Flexer, C., Baumgarner, J. & Wilcox, M.J. (Ed.). (1990). Children with dual sensory impairments series: Guidelines for determining functional hearing in school-based settings. (Available from Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278).

Instructional Support System
of Pennsylvania
Pennsylvania Department of Education
Pennsylvania Department of Public Welfare

FACT SHEET #4

PA DEAFBLIND PROJECT

Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth with Deafblindness

The Project is a four year (1999-2003) federal grant program that provides the state of Pennsylvania with consultation, training and technical assistance for families, educators and service providers working with infants, toddlers, children and youth (birth through age 21) who are deafblind or at risk for deafblindness. The Project is staffed by education consultants, parent liaisons and a project assistant.

Project Goals and Activities

Ensure early and accurate identification of children and youth who are deafblind or at risk for deafblindness.

- Ongoing data collection and monitoring of the status of children and youth who have been identified as at risk for deafblindness, or as deafblind
- Availability of materials about screening and identification of sensory impairments
- Dissemination of disability-related materials and information on effective practices
- Provision of regional training of early intervention and early childhood service providers
- Information packets for newly identified children and youth

Enhance local capacity through the provision of training and technical assistance for educators and service providers of children and youth with deafblindness.

- Inservice and pre-service training via state-wide, regional, or local workshops
- Videoconferences and teleconferences
- Study groups and focus groups
- Linkages with state-wide training for students with sensory impairments
- Annual summer institute with on-site follow up
- BEST (Building Effective Student Teams) training
- Effective practices in deafblind education
- Interagency team approach to intervention
- Other requested activities

Support families through involvement in educational planning, access to information, consultation and training opportunities.

- Availability of family-to-family support
- Team-based technical assistance, involvement in educational planning
- Training opportunities related to most effective practices in deafblind education
- Regional Family Learning Days, State-wide Family Learning Weekends
- Any inservice activities offered by the Project
- Materials from an extensive lending library
- Monthly phone conference calls of study groups and focus groups
- Other requested activities

Continue and expand partnerships with other local state, and national agencies serving individuals who are deafblind in order to impact upon the quality of services for children and youth who are deafblind.

- Local transition agencies and teams
- The early intervention lead agency (Department of Public Welfare)
- The PA Parent Training and Information (PTI) center (Parent Education Network)
- The PA Department of Education Comprehensive System of Personnel Development (CSPD)
- The State Improvement Grant (SIG)
- The National Technical Assistance Consortium for Children and Young Adults who are Deafblind (NTAC)
- Helen Keller National Center
- Others as related

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Information

Education consultants are accessible by telephone, voice mail and e-mail.

The Project has a page on the Instructional Support System web site http://www.cisc.k12.pa.us under the Deafblind Project. This site offers a number of choices, such as activities, information sheets, links to other resources (e.g. DB-Link: National Clearinghouse on Deafblindness).

Information updates and targeted mailings are automatically sent to families and contacts of an identified child as well as to school districts, intermediate units, early intervention programs and county MH/MR offices, unless otherwise notified.

Information Pages available from The Project:

- Overview on Deaf-Blindness (DB-LINK)
- Questions and Answers About The Project
- Questions and Answers About The Annual National Deafblind Census
- Psychological Evaluation of Children Who Are Deaf-blind: An Overview With Recommendations For Practice (DB-LINK)
- Considerations in IEP Development For Children Who Are Deafblind
- Tips For Students With Usher Syndrome
- Request for additional resources form

Federal Definition of Deafblindness

The term "children with deafblindness" means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related service to address their educational needs due to these concurrent disabilities.

The term "infants and toddlers with deafblindness" means children from birth through age 2 who are experiencing developmental delays in hearing and vision, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in hearing and vision, or are at risk of having substantial developmental delays in hearing and vision if early intervention services are not provided.

For more information, please contact:
Nancy Lehr, Project Assistant
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2793
1-800-360-7282 (in PA only); 717-541-4960, extension 3115
Fax: 717-541-4968
nlehr@cisc.k12.pa.us

Further information concerning CISC services is available by calling toll free 800-360-7282 (PA only); 717-541-4960
or writing to CISC, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2793
Fax: 717-541-4968
Internet Address: http://www.cisc.k12.pa.us

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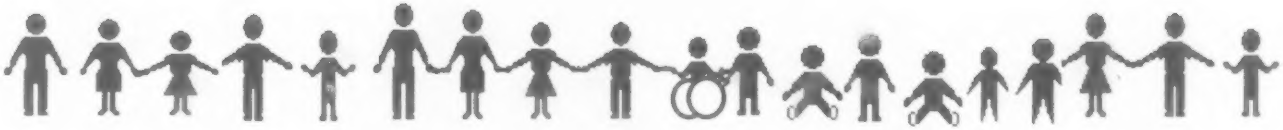
CONNECTIONS

I'D LIKE TO

MAKE



FAMILY LEARNING RETREAT
NITTANY LION INN - STATE COLLEGE
APRIL 11, 12, 13, 1997

My name is Tony K. I am 12 years old.

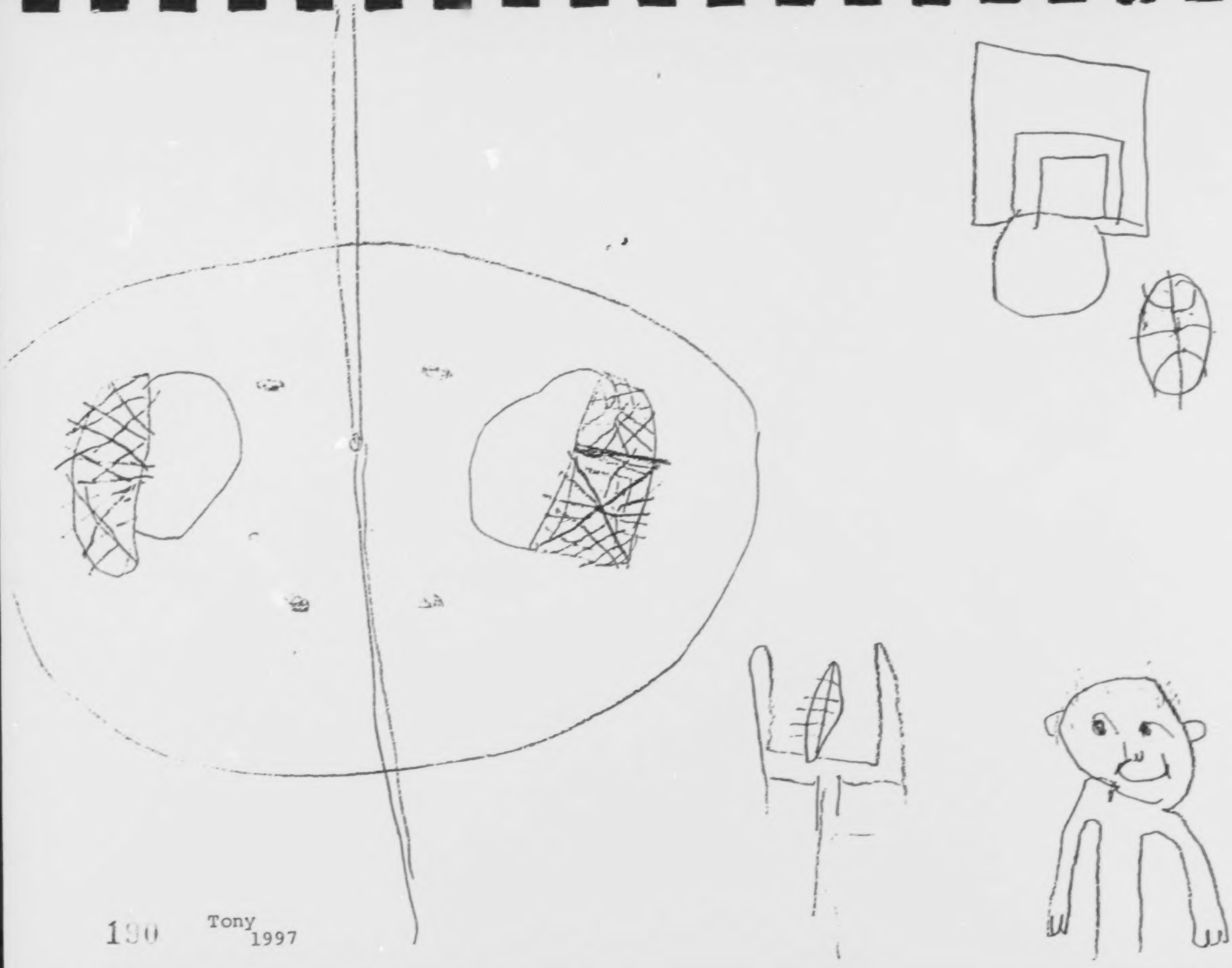
My most fun thing to do in my community is skiing and bowling.

My favorite neighbors are Cody, Marion and Dalene. They are real friends and lots of fun.

If I could have dinner with anyone, I would like to go with the Anaheim Mighty Ducks hockey team. I really love hockey and "The Ducks".

If I could go anywhere in the world, I would go to the Indy 500. I am named after Tony Hulman whose family owns the Indianapolis Speedway.

The connection I would most like to make in my community is with someone to help improve my education.

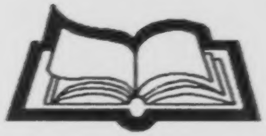


Tony
1997

My name is Cherish D. and I am seven years old.

If I could have dinner with anyone, I would like to go with Shawn because he is my best friend.

If I could go anywhere in the world, I would go to Disney World or Disney Land because I love rides.



My name is Salvatore G. and I am five years old.

My most fun thing to do in my community is to play outside with other children.

My favorite neighbors are Trudy and Buzzy and Erick. Erick is two years old and I love to play with him.

If I could have dinner with anyone, I would like to go with Elmo from Sesame Street because he is big and red and my favorite character.

If I could go anywhere in the world, I would go to the BIGGEST childrens' library because I love books.

The connection I would most like to make in my community is to be able to communicate verbally with members of the community and to be accepted for what I am.

My name is David H. I am five years old.

My most fun thing to do in my community is going swimming at the YWCA.

My favorite neighbors are Ron and Margie, and Jim and Chris, because they fuss over me when I do new things.

If my family could have dinner with anyone, we would like to go with Governor Tom Ridge because I would like to tell him to stop taking away programs from handicapped children that may help me in the future.

If I could go anywhere in the world, I would go to Disney World because it is a place that guests with disabilities are treated with kindness.

The connection I would most like to make in my community is to help others in need by touching their hearts with the love of God.

My name is Rebecca Jean W. *I am four and one-half years old.*

My most fun thing to do in my community is walk to the playground, about five blocks away.

My family just moved into a new house in March and I haven't met many neighbors yet.

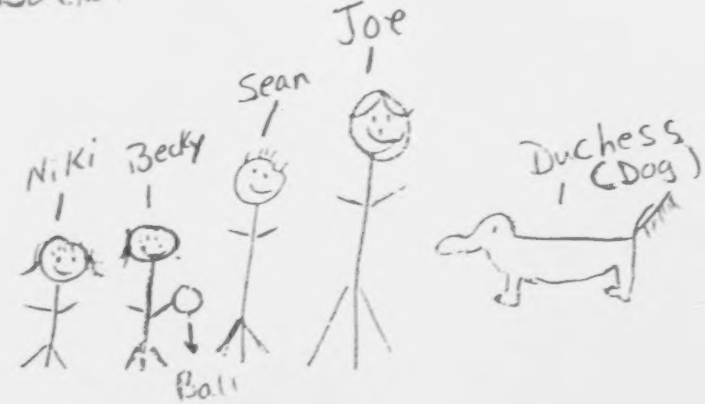
If my family could have dinner with anyone, We would like to go with Newt Gingrich, Governor Ridge and Senator Santorum. I would like them to experience the life of a deafblind person -- let them try to find their, cup, plate, spoon; how about the bathroom; let's not forget the noise level with hearing aids.

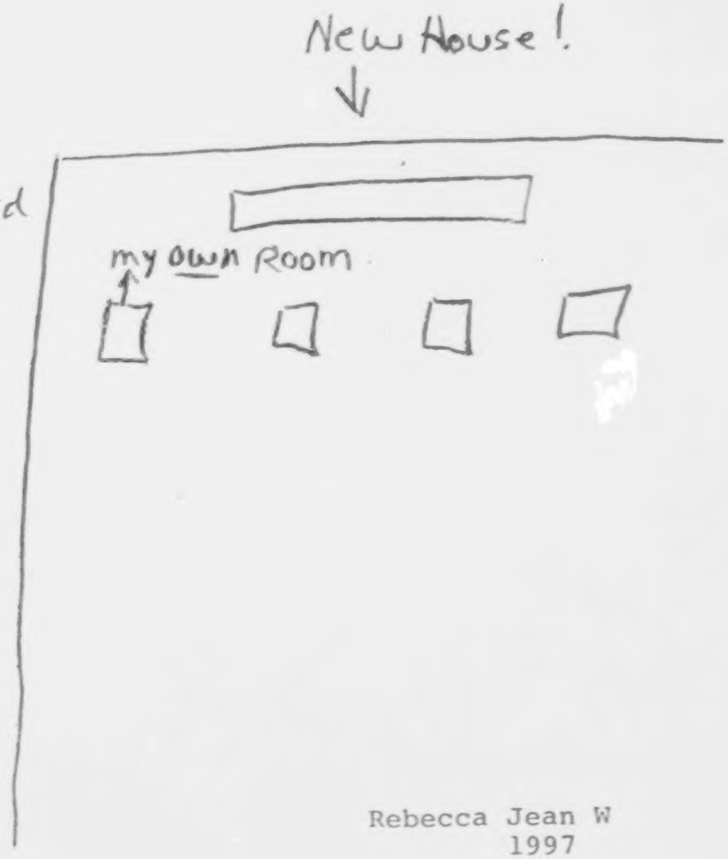
If I could go anywhere in the world, I would go to Italy because I love pasta.

What my family would most like to do in our community is to educate the service agencies regarding the needs of all the special children instead of being predominantly centered for adults.

Playing Ball with Duchess

I throw the ball & Duchess fetch's it & brings it back!


Joe
Sean
Niki
Becky
Ball
Duchess (Dog)


New House!
Backyard
my own Room

Rebecca Jean W
1997

My name is Alex B. and I am five years old.

My most fun thing to do in my community is visit McDonald's Playland, especially the ballpit.

My favorite neighbor is Joni, my babysitter. She takes the time to sit and read books with me. She waits for me to initiate play and follows my lead.

If my family could have dinner with anyone, we would like to go with Governor Ridge. I would explain to him how important it is to fund MY education, as well as my sisters' education.

If I could go anywhere in the world, I would go to Disneyworld because I love Mickey Mouse.

The connection I would most like to make in my community is to go to my neighborhood school instead of riding a bus so far away.

My name is George Z.

I am three and one-half years old.

My most fun thing to do in my community is going to my brother's basketball games.

My favorite neighbors are the ones who don't notice me as different. They include me and treat me like all the other children.

If I could have dinner with anyone, I would like to go with any person who wanted to "write me off". I would want to effectively communicate with them about their shortcomings.

If I could go anywhere in the world, I would go anywhere that I could communicate with others.

The connection I would most like to make in my community is with "my" peers.

My name is Jacob J. and I am almost five years old.

My most fun thing to do in my community is going swimming at Quakertown Swimming Pool.

Katie is my favorite neighbor. She is a great babysitter and she likes to play with me.

If I could have dinner with anyone, I would like to go with my family to McDonald's because they have the most awesome french fries!

If I could go anywhere in the world, I would go to Walt Disney World because I love to go on amusement park rides -- the more motion, the better!

The connection I would most like to make in my community is making people understand that kids are kids regardless of their special needs.

My name is Billy G. and I am six years old.

My most fun thing to do in my community is play Little League T-ball.

My favorite neighbors are Anthony, Maria, Jessica and Robin because they think I can walk and they talk to me.

If I could have dinner with anyone, I would like to go with Barney because I like his annoying voice.

If I could go anywhere in the world, I would go to Florida. It's warm there and I could play outside.

The connection I would most like to make in my community is to prove that I am a kid too.

My name is Lily May L. I am 16 years old.

My most fun thing to do in my community is swimming.

My favorite neighbor is Grandma because I really like to be with her.

If I could have dinner with anyone, I would like to go with Drew Barrymore.

If I could go anywhere in the world, I would go to Hollywood because I want to be in the movies.

The connection I would most like to make in my community is to find work.

My name is Nada G. I am nine years old.

My most fun thing to do in my community is shopping.

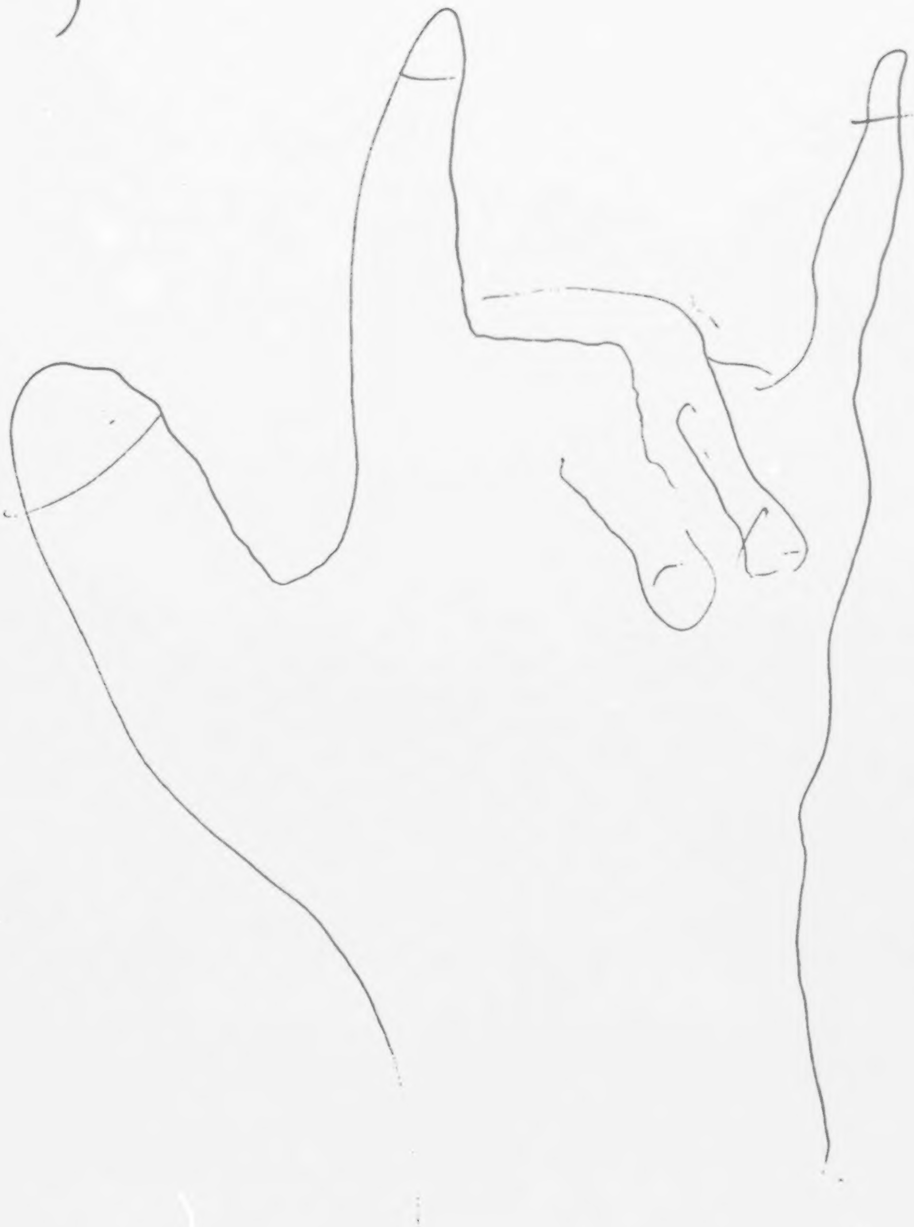
I have wonderful neighbors who love me and bring me gifts.

If I could have dinner with anyone, I would like to go with my family because I enjoy being with them.

If I could go anywhere in the world, I would go to Egypt. Grandma and Grandpa live there and I love them very much.

The connection I would most like to make in my community is with other children in the area.

I Love You



Nada G
1997

I'm CH. My outings are greatly limited due to health concerns. But when health and weather permits, I like to accompany my family to the local Pizza Hut. Although I cannot yet eat pizza, I enjoy the sounds and smells. All the waitresses stop to touch and greet me.

The thing I and my family would like most is to receive a communication board.

My name is Vivian Nicole M. and I am three years old.

My most fun thing to do is play and learn with other children.

My favorite neighbors are Elaine and Sean because they talk to me and Elaine holds me.

If I could have dinner with anyone, I would continue to go with my mom because I like the way she feeds me.

If I could go anywhere in the world, I would go to Florida because it is warm and sunny there.

The connection I would most like to make in my community is to play with lots of other kids my age.

We greatfully thank the families

for their contributions

to this booklet.

❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖❖

PA Deafblind Project

PA DEAFBLIND PROJECT
REQUEST FOR RESOURCES

INSTRUCTIONS: Please complete the identifying information below and indicate which items you would like to receive. Mail this form to:

Nancy Lehr
PA Deafblind Project
6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764

Student Name ______________________________ Date ______________

Your Name ____

Parent ____________ Educator ____________ Other ______________

Address ____

____

Check items you would like to receive:

___ 1. *Pennsylvania Deafblind Project Fact Sheet*
___ 2. *Family-friendly Deafblind Project Brochure*
___ 3. *Questions and Answers about the Project*
___ 4. *Questions and Answers about the Annual National Deafblind Census*
___ 5. *Questions and Answers About Transition Team Partnership*
___ 6. *Behavioral Issues in Children with Multiple and Sensory Impairments*
___ 7. *Considerations in IEP Development for Children who are Deafblind*
___ 8. *Cues: Touch, Object, Environmental*
___ 9. *Information for the Audiologist*
___ 10. *Information from the Audiologist*
___ 11. *It Begins With Communication*
___ 12. *A Letter from Janna (about a student's use of technology)*
___ 13. *Parents' Perspectives*
___ 14. *Preferred Activities and Motivators*
___ 15. *A Story About Alex (about a student's participation in the community)*
___ 16. *A Story About Zenola*
___ 17. *Surfing the Web*
___ 18. *Tips for Students with Usher Syndrome*
___ 19. *Communication Interactions: It Takes Two (DB-LINK)*
___ 20. *Early Interactions with Children who are Deaf-Blind (DB-LINK)*
___ 21. *Expressive Communication (DB-LINK)*
___ 22. *The Importance of Orientation and Mobility Skills For Students Who Are Deafblind (DB-LINK)*
___ 23. *Overview on Deaf-Blindness (DB-LINK)*
___ 24. *Psychological Evaluation of Children who are Deaf-blind: An Overview with Recommendations for Practice (DB-LINK)*
___ 25. *Receptive Communication (DB-LINK)*
___ 26. *Recreation and Leisure (DB-LINK)*
___ 27. *Talking the Language of the Hands to the Hands (DB-LINK)*

(All DB-LINK documents are specific to children who are deafblind.)

nel 12/98

And from various authors:

___ 28. *Assessing Young Children with Dual Sensory and Multiple Impairments: Ages Birth to Five Years*

___ 29. *Assessing the School-Age Student with Dual Sensory & Multiple Impairments: Ages 6-15*

___ 30. *Assessing the Transition Needs of Young Adults with Dual Sensory and Multiple Impairments*

We're on the web!
http://www.cisc.k12.pa.us

For Your Information

The main office of the PA Deafblind Project is located at the Central Instructional Support Center (CISC) in Harrisburg. The web page for the PA Deafblind Project can be accessed through the CISC web page at http://www.cisc.k12.pa.us.

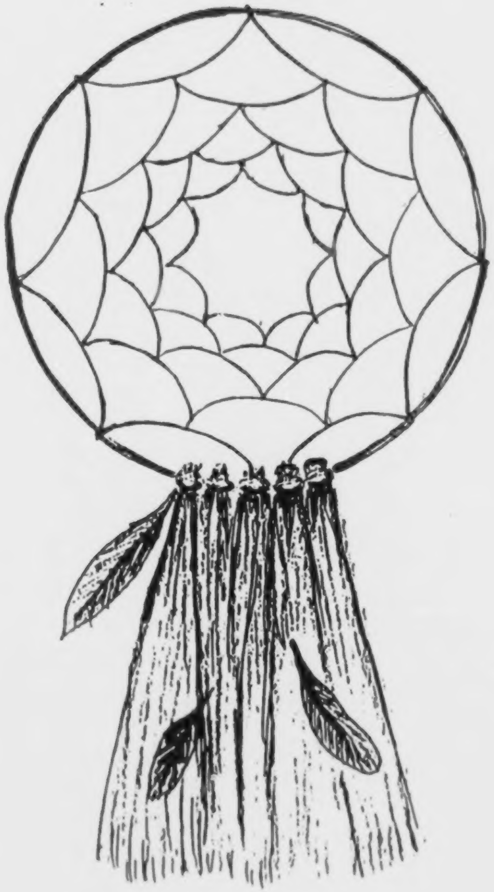
Although this web site is undergoing heavy reconstruction, the Project currently has information, resources, links to other sites related to deafblindness, and e-mail to Project staff. It is also possible to link to the text of IDEA '97 and the recently released rules and regulations that apply to IDEA '97 via the CISC web page.

Contacts in Pennsylvania

Juli Baumgarner Education Consultant PA Deafblind Project 5347 William Flynn Highway Gibsonia, PA 15044-9644 Phone: 800-446-5607, ext. 238 or 724-443-7821, ext. 238 e-mail: baumgar@wisc.org	Jeanne Gardier Education Consultant PA Deafblind Project 1200 Line Street Archbald, PA 18403 Phone: 800-360-7282, ext. 3132 or 717-541-4960, ext. 3132 e-mail: gardierj@ns.neiu.k12.pa.us	Mary R. Frey Education Consultant PA Deafblind Project 6340 Flank Drive, Suite 600 Harrisburg, PA 17112-2764 Phone: 800-360-7282, ext. 3005 or 717-541-4960, ext. 3005 e-mail: mfrey@cisc.k12.pa.us

If you are unfamiliar with your state resources, we can give you the name of the contact for your state.

THE
DREAM
I
WANT
TO
CATCH



PENNSYLVANIA DEAF-BLIND PROJECT
1996 FAMILY LEARNING RETREAT

My name is Chiffon Jackson. I am 15 years old.

I am proud when I get good grades, and when I accomplish goals I had my heart set on.

I am really good at singing and drawing, but I like to hide my talents.

I'm happiest when I am with my friends and family.

I am looking forward to working this summer and being a colorguard captain in marching band next year.

If I could do anything I wanted, I would join the Marines and have a large family -- and maybe even sing professionally.

The dream I want to catch is to go to college and be the type of person my family and I can be proud of.

My name is Stair "Billy" Gerlach. I am five years old.

I am really proud when I reach certain goals that I and my family work hard to achieve.

I am good at laughing, getting in a crawling position, making the people around me smile, and surprising people.

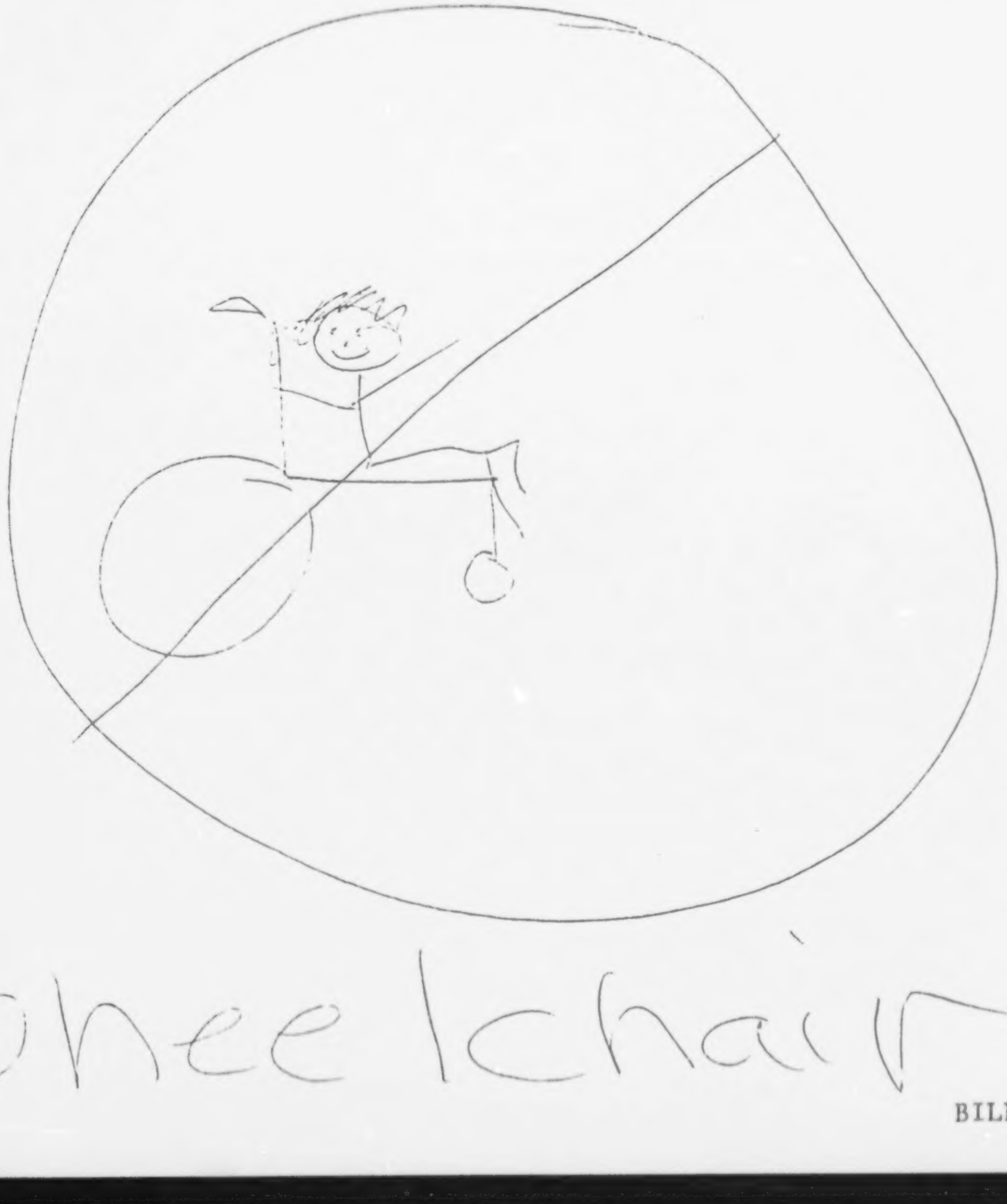
I am happiest when my brother, Bo, kisses me, and when I'm with my family.

I look forward to walking some day.

If I could do anything I wanted, I would say, "I love you Mom."

The dream I want to catch is to get better.

NO MORE



wheelchair

BILLY GERLACH

Hi. I'm Sean McHale and I am 21 years old.

I am really proud when I do things by myself.

I'm good at having fun and making people laugh.

I am happy when I am with my dog and having fun with my friends.

I'm really looking forward to graduation.

If I could do anything I wanted, I would walk, see better and hear a song.

The dream I want to catch is getting married to my friend, Tracy.

I am so proud because I am progressing every day.

I'm really good at playing in the water and on my Sit 'n Spin. I look forward to swimming at the swimming pool this summer.

I am happiest when I am with my family.

If I could do anything I wanted, I would always be barefooted.

The dream I want to catch is to go to Disney World!

Jacob Jarrell
Age 4

My name is Samantha Parry and I am two and one-half years old.

I am most proud when I please others.

I am really good at spinning.

I am happiest when I am held and loved by Mom and Dad.

I am looking forward to the rest of my life.

I like music and vibrating objects.

The dream I want to catch is to be understood.

I am proud when I get a good report card.

I am really good at composing music.

I am happiest when it's Friday -- no school for two days.

I am looking forward to getting a good education.

If I could do anything I wanted, I would go to the zoo and look at the animals -- explore them with my hands.

The dream I want to catch is to be a good musician.

John Holcomb
Age 13

Hi, I am Katy Molyneaux and I am four years old.

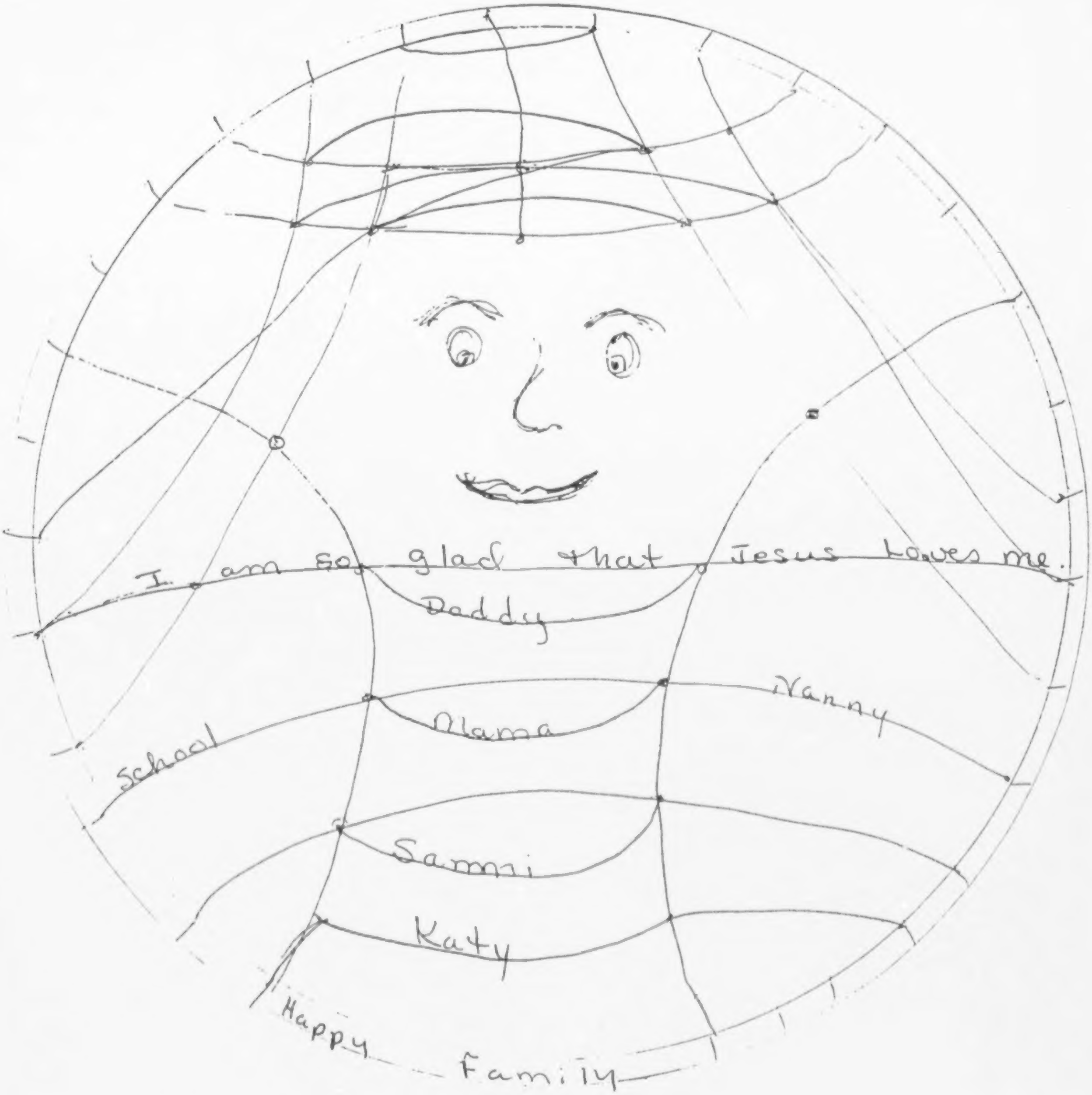
I am proud when Daddy or Mama or anyone praises me for my accomplishments.

I'm really good at singing.

I am looking forward to not being afraid of walking and crawling.

Sometimes I get so frustrated and angry because I am unable to do some things by myself; if I could do anything I wanted, I would be independent.

The dream I want to catch is to have more interaction with my family and more movement for myself.


I am so glad that Jesus Loves me.
Daddy
Nanny
Mama
School
Sammi
Katy
Happy Family

BEST COPY AVAILABLE

Katy Molyneaux

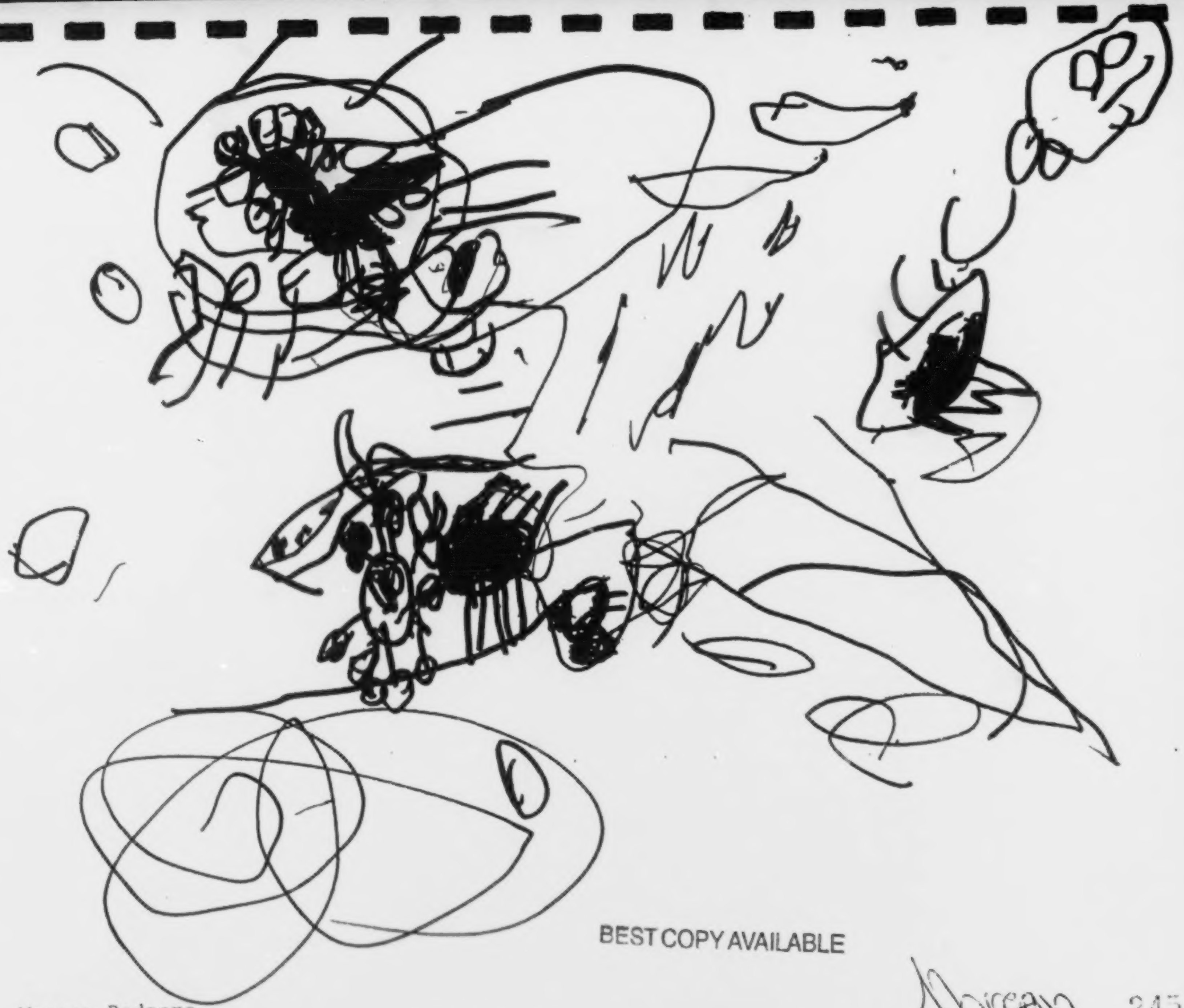
My name is Morgan Rodgers.
I am four years old.

Whenever I accomplish something new, everyone claps and gives me a big kiss and that makes me proud.

I am really good at drawing and completing puzzles.

I am happiest when playing with my Raggedy Ann dolls.

The dream I want to catch is to have full communication with others.



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Morgan Rodgers

Morgan

Hello, my name is Nada Ghattas. I am nine years old.

What makes me proud is my family's love and support, my school teacher and her efforts to help me to be independent.

I am really good at spelling words and memorizing them and signing them.

I am happiest when I have ice cream after dinner and candy after I finish my homework.

I am looking forward to the summer and swimming in the pool and going to the beach.

If I could do anything I wanted, I would play outside all day with my dolls and draw pictures of flowers and trees.

The dream I want to catch is to be a big girl and learn more about computers and be independent.

Hi, my name is Christopher Griffith. I am six years old.

I am really good at knowing the color "red".

I am proud when I take my lost baby teeth to school for show and tell.

I am happiest when I'm among other children who give me attention, and when I get onto the bus to go to school because the bus driver sings songs with me.

I look forward to my meals and looking at books and pictures.

If I could do anything I wanted, I would be better able to communicate so I would not get so frustrated trying to tell people what I'm thinking.

My name is Troy Michael Langhout. I am six years old.

I am really good at swimming. I have no fear of the water. I love to be under the water a lot.

I am happiest when I am eating. I am also happy when I am tickled and cuddled by my mom and brother.

I look forward to going to school everyday. I love to ride the school bus. I enjoy using my walker at school and all the fun activities at school.

If I could do anything I wanted, I would run and play like other children, especially with my twin brother.

The dream I want to catch is to have sight to see my mom and brother and to be able to talk to them. I know my family, including my grandmother, must have these dreams also.

Hello, my name is Chelsey Hartman. I am 20 months old.

What makes me proud is trying real hard to hold a crawling position with my head held high -- and Mommy tells me how proud she is of me for trying.

I am really good at smiling when people touch me gently while talking to me.

I am happiest when I am in my new Kid Kart and go for a ride.

I am looking forward to rolling over and sitting up by myself.

If I could do anything I wanted, I would run, play and chatter like my twin sister.

The dream I want to catch is making people understand what I want.

Hello, my name is G. Alexander Black. I am four and a half years old.
What makes me proud is learning a new skill.
I am really good at walking.
I am happiest when eating, or snuggling with my Mom and Dad.
I am looking forward to learning how to use an augmentative communication device.
If I could do anything I wanted, I would go somewhere without someone standing watch over me.
The dream I want to catch is more independence through improved communication.

Hello, my name is Nafisa Zuri. I am 22 years old.

I am really good at different vocational skills such as planting, sorting and stacking.

I am happiest when I have applesauce and ice cream to eat.

I am looking forward to moving to my own place.

If I could do anything I wanted, I would learn to talk to my parents, siblings and peers.

The dream I want to catch is an independent living situation, as much as is possible.

My name is Timothy Zabroske and I am seven years old.

What makes me proud is being able to help empty the grocery cart.

I am really good at making friends and being friendly.

I am happiest when I am with my family -- eating dinner, going for a ride, being in church.

I am looking forward to going to summer school at Camp Pennwood and taking horseback riding lessons.

The dream I want to catch is to communicate so everyone could understand me.

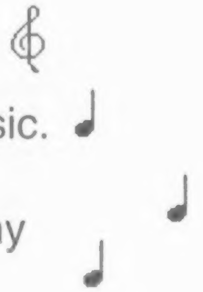
My name is Alvatore T. Gambino. I am four and a half years old.

What makes me proud is when I sing or do something and people clap for me.

I am really good at singing.

I am happiest when I am swimming in the pool.

If I could do anything I wanted, I would sing and make music.



The dream I want to catch is to communicate better with my family.

Hi, my name is David Allen Hilderbrand, Jr. I am four and a half years old.

What makes me proud is when I go on my potty.

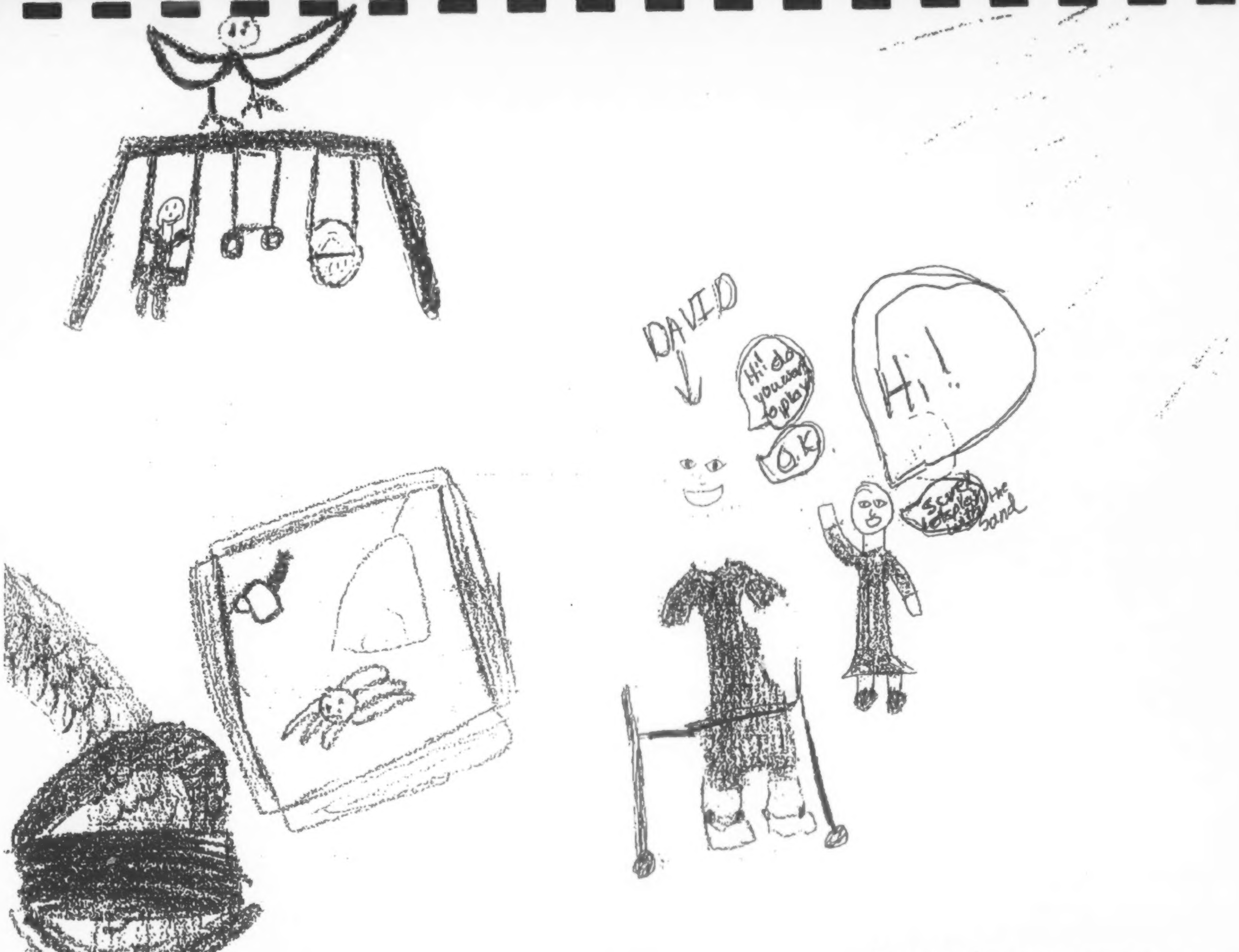
I am really good at sitting by myself in my chair. I am also good at making verbal sounds to tell my family what I need.

I am happiest when I get my bath and my mom sprays water on me with the shower sprayer.

I am looking forward to summer when I swim with my sister in our "blow-up" swimming pool.

If I could do anything I wanted, I would run and play with my sister and other children.

The dream I want to catch is for all people to accept me as I am and not according to my disabilities.


DAVID
Hi! do you want to play
O.K
Hi!
Sure! lets play with the band

David Allen Hilderbrand, Jr.

Hello. My name is Rebecca Jean Weaver and I am three years old.

What makes me proud is being able to get around by myself.

I am really good at undressing myself and using my cup.

I am happiest when I am outside and, also, when I play in water.

I am looking forward to suumer at the pool and, then, going back to school.

If I could do anything I wanted, I would be able to talk.

The dream I want to catch is to be able to tell Mommy and Daddy and my family how much I love them.

Hi. My name is George Zielinski. I am three years old.

What makes me proud is learning something new after I worked hard to learn it.

I am happiest when I sit and cuddle with Mom or Dad.

I am looking forward to making new friends.

If I could do anything I wanted, I would ride a bike.

The dream I want to catch is to be a kid.

What makes me proud is being just me.

I am really good at smiling.

I am happiest when I have everybody's attention.

I am looking forward to my next vacation at Disney World.

If I could do anything I wanted, I would run.

The dream I want to catch is happiness.

Taylor Marie Blackburn
Age 5

Pennsylvania Deafblind Project
6340 Flank Drive, Suite 600 • Harrisburg, PA 17112-2764
800-360-7282 in PA only or 717-541-4960

March 15, 1999

Dear (name),

Recently, the Pennsylvania Deafblind Project (part of the Pennsylvania Department of Education, Instructional Support System of Pennsylvania) conducted the federally required count of children and youth with both a vision and hearing impairment. We were informed by either your school district, the intermediate unit or your early intervention agency that your child either has or may have a combination of a vision and a hearing impairment.

"Deafblind" is a term used to identify a child with a combined hearing and vision impairment. "Deafblind" does not necessarily mean that your child cannot see or hear at all. Nearly all children with deafblindness have some useable vision or some useable hearing. Because there are not many children with deafblindness, Pennsylvania and the federal Department of Education have decided to offer increased support to families with a child with combined hearing and vision impairments.

We would like to offer you information, support, and the opportunity to be connected with other families who may have similar situations to yours. The Pennsylvania Deafblind Project assists families and educational teams to plan and provide appropriate services to your child.

Enclosed are materials about the Project. You can expect to receive information and flyers about upcoming events. You may be particularly interested in our annual statewide Family Learning Retreat, regional Family Learning Days, and other family involvement activities. Additionally, your family is welcome to attend any of the professional staff development activities that are sponsored by the Project. Also, we offer materials (e.g., books, videotapes) on loan that may be helpful to your family in interacting with your child who has a combined vision and hearing loss.

Please feel free to call the Project (800-360-7282, extension 3115) if you have any questions or if you wish to be taken off our mailing list. Our project assistant, Nancy Lehr, can direct your call to one of two education consultants and several family liaisons who are available to speak with you. If it is more convenient for you, please return the enclosed "I would like to be contacted . . .." postcard so that a project staff member can get in touch with you.

Sincerely,

Mary R. Frey
Education Consultant

Juli Baumgarner
Education Consultant

Yes, I would like to be contacted by the PA Deafblind Project

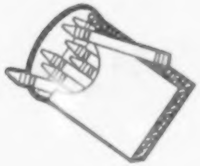
___ by an educational consultant
___ by a family liaison
___ by both
___ Please contact me by phone. My phone number and best time to call is: (   ) ______________________________
___ Please contact me by e-mail. My e-mail address is:
____

Some questions I have are: ______________________________
____
____
____

Name ______________________________
Address ______________________________
____

BEST COPY AVAILABLE

CHILDREN OF THE RAINBOW STORIES



DIVERSITY: COLORS OF THE RAINBOW

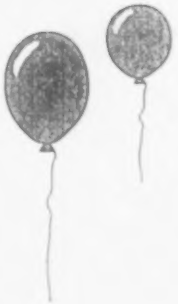
Hi, my name is Derrick and I am 18 months old.

I live in a house with my Mommy, Daddy and two sisters.

My Mommy and Daddy are helping me build a communication system

I move around by sitting up, then falling over and rolling.

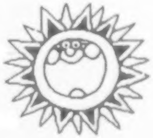
What I like to play with most is my family because I love when my family plays with me.

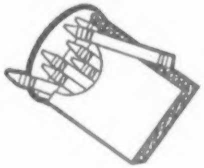


A meal special to my family is any meal at which we can all be together.

A holiday tradition in my family is putting the angel on top of our Christmas tree.

My family celebrates special events by taking lots of pictures so we can always look back and enjoy the special day all over again!

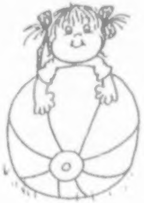




DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is Chelsey and I am three and one-half years old.

I live in a house with my Mom, two sisters, and one brother.



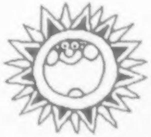
I communicate with facial expressions, gestures, and shaking my head for "yes" and "no".

I move around by someone pushing my kid kart.

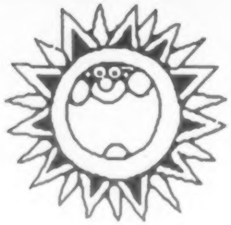
I like to play most with my carnival music box because I get to pick the type and songs I want to hear.

A meal special to my family is pizza.

My family celebrates special events by going to Pizza Hut.



DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Daniel and I am three years old.

I live in a house with my Mom, Dad and sister.

I communicate with facial expressions and body movement.

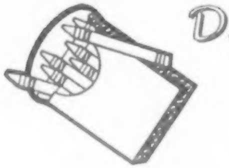
I move around by crawling, riding bike,
and "cruising" furniture.

I like to play mostly with light-up toys.

A holiday tradition in my family is Sunday's at Grandma's house.

My family celebrates special events by inviting company.

DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Sean and I am four years old.

I live in a house with my Mommy, Daddy and sister.

I communicate with a little of everything except speech.

I can move around by walking.

What I like to play with most are things
that spin or turn like wheels.
I like to watch them go round and round.

A meal special to my family is tuna casserole -- my favorite.

A holiday tradition in my family is going to Mass together on Christmas eve, then having dinner, then reading the book "Twas the Night Before Christmas".

My family celebrates special events by having everyone -- my Mom, Dad, Cissy, Grammy, Pappy, Aunt Anne, and sometimes Uncle Kevin -- get together for a special celebration dinner.

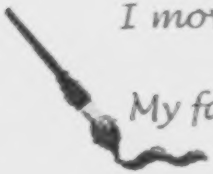
DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is Vivian and I am four years old.

I live in a rowhome with my Mom , Dad, sister and brother.

I communicate with facial expressions, gestures and different crys.

I move around in my wheelchair, or Mommy carries me.

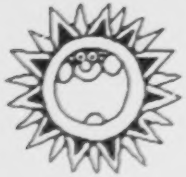


My favorite color is yellow because I look nice in yellow.

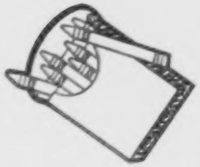
I like to listen to music and hug my baby doll.

A tradition in my family is to give hugs all the time.

My family likes to listen to music and dance.



DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Brittany and I am five years old.

I live in a house with my Grandpa, Grandma,
sister, aunt and two uncles.

I communicate with facial expressions, gestures,
body movement, and some tactile cues.

I move around by walking.

My favorite color is red because I can see the color red.

I like to play with dolls and stuffed animals.
I like to hold them and talk to them.

A meal special to my family is fried chicken
and homemade french fries.

A holiday tradition in my family is opening Christmas gifts on
Christmas eve.

My family celebrates special events by preparing
a nice family dinner.

DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is Rebecca. I am five and one-half years old.

I live in a big house with my Mom, Dad,
sister, two brothers and my dog.

I communicate by talking -- I'm up to 30+ words now!

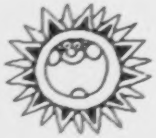
I can run and walk. I like being pushed/pulled in my wagon.

My favorite colors are red and orange because
I can see those colors the best.

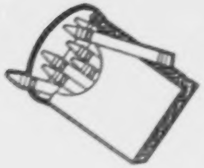
What I like to play with most is my new swimming pool
from Make-a-Wish. I love to kick in the water.

A meal special to my family is spaghetti and angel food cake.

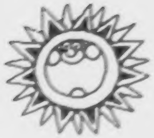
A holiday tradition in my family is Christmas day brunch
when EVERYONE comes to my house.



My family celebrates birthdays by singing "Happy Birthday"
and then I yell "yeah!" and clap for everyone.



DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Alex and I am six years old.

I live in a house 🏠 with my Mom, Dad and two sisters.

I communicate with gestures, eye gaze,
sign language and pictures.

My favorite colors are red and black
because that's what color Mickey Mouse is
and I love Mickey Mouse!

What I like to play with most are books and
musical toys because of the bright pictures and loud sounds.

A meal special to my family is turkey,
stuffing and mashed potatoes.

A holiday tradition in my family is traveling to Grandma's and Grandpa's for Thanksgiving. They live near the beach so I get to visit the ocean.

My family celebrates special events by joining friends and family for meals and fun.

DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is David and I am six years old.

I live in a house with my Mom, Dad, sister,
dog (Abby), and Bunny (Abbit).

I communicate with facial expressions and gestures.

I move around by walking with AFO's on and
adult assistance or scooting on the floor.

My favorite color is red or yellow because it is so bright.

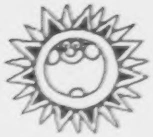
What I like to play with most is Tickle Me Elmo.
because it is red and furry and it laughs when I drop it or throw it.

A meal special to my family is turkey, gravy,
mashed potatoes, sweet potatoes and applesauce.

Holiday traditions in my family include coloring Easter eggs
and baking a birthday cake for Jesus at Christmas.

My family celebrates special events by visiting Grandma and Pap Pap.

DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Salvatore and I am seven years old.

I live in a house with my Mom, Dad, sister,
aunt, uncle and two cousins.

I communicate by talking and signing.

I move around by walking plus use of a wheelchair.

My favorite color is green because
the grass and trees are green and I like to be outside.

What I like to play with most is my Sega game
because I like the bright colors on T.V.

A meal special to my family is pasta.

A holiday tradition in my family is having
our family's secret punch.

My family celebrates special events by making
special foods and having balloons to mark the event.

DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is Billy and I am seven years old.

I live in a house with my Mom, Dad, sister and two brothers.

I communicate with facial expressions and some signs.

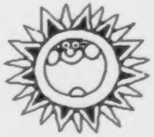
I move around with my walker and roll all over the place.

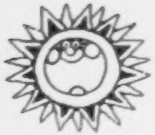
My favorite color is red because it has a
good contrast with white.

What I like to play with most is my "See & Say"
because I can bang it and it does things.

A meal special to my family is spaghetti -- 'cause
Mom cooks it four days a week.

My family celebrates special events by eating out.





DIVERSITY: COLORS OF THE RAINBOW

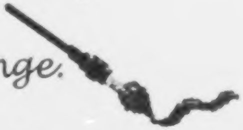
Hi, my name is David and I am eight years old.

I live in a house with my Mom, Dad and brother.

I communicate by talking

and I move around by walking.

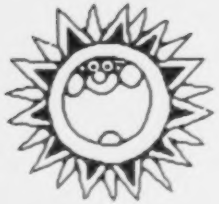
My favorite color is orange.



I like to play with my Legos
because I love to build things.

A meal special to my family is Chinese foods.

My family celebrates special events by eating out.



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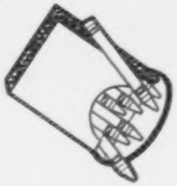


Hi, my name is Zac and I am 11 years old (that's what my birth certificate says).

I live in a house with my Mom, Dad, brother (Josh), and sister (Faith).

I communicate with a few basic signs and non-verbal cues.

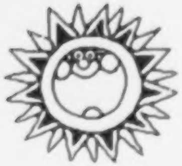
I move around by walking; sometimes I use a wheelchair-- like at the mall.

Mostly, I like to swing on the swings.

A tradition in my family is having family and friends over for the holidays.

My family celebrates special events by going to McDonald's for my birthday and I get to eat all the french fries, McNuggets, and Coke I want.

DIVERSITY: COLORS OF THE RAINBOW



Hi, my name is Brenson and I am 14 years old.

I live in a house in the country with my Mom, Dad,
two sisters and three brothers.

I communicate by talking.

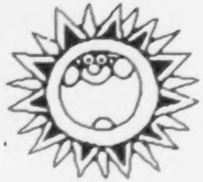
I move around with a sighted guide.

What I like to do most is listen to music
because it makes me move.

A meal special to my family is chicken, greens,
potato salad and hot rolls.

A holiday tradition in my family is
celebrating Kwanza.

My family celebrates special events by
having a big family dinner.



DIVERSITY: COLORS OF THE RAINBOW

Hi, my name is Lily and I am 17 years old.

I live in a house 🏠 *with my Mom.*

I communicate by signing.

My favorite color is black because --
I like black.

I like to play basketball.

A meal special to my family is turkey and pies.

My family celebrates special events by
having cook-outs and big dinners.

TOGETHER WE'RE BETTER

Stories

Learning Through Play and Humor

Play is a child's work . . .
children play to learn,
to grow and to experience
the world around them.

Pennsylvania Deafblind Project
Family Learning Weekend ◆ June 25, 26, 27, 1999

TOGETHER WE'RE BETTER

Hi, my name is Micaela and I am 2 years old.

I like to play and have fun. My favorite toy is sound gym. I like to watch lights.

My favorite person to play with is Mommy because she knows the things I like.

I think it is funny when Miranda tries to catch bubbles with her mouth.

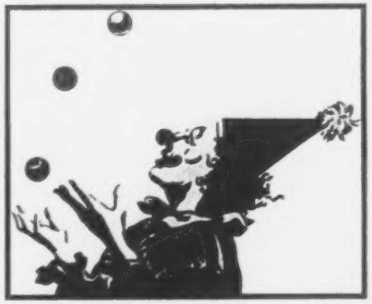
The best time I ever had was when we went to Camp Connection.

I think the funniest TV show or song is "Teletubbies."

A sound or noise that makes me laugh is my Daddy's voice.

The color that makes me happiest is yellow.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.



TOGETHER WE'RE BETTER

Hi, my name is Hunter and I am 2 1/2 years old.

I like to play and have fun. My favorite toy is my shopping cart.

My favorite person to play with is my Dad. He is really rough (wrestles) and makes me laugh.

I think it is funny when my mom and dad tickle me.

The best time I have is when I ride the merry-go-round.

I think the funniest TV show is "Teletubbies."

The colors that make me happiest are red and yellow.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

TOGETHER WE'RE BETTER

Hi, my name is Chelsey and I am 4 years old.

I like to play and have fun. My favorite toys are my musical toys and my crawler.

My favorite person to play with is my special tutor, Fanny. Fanny knows how to make me work and still have fun.

I think it is funny when Mommy takes the "tickle tummy road."

The best time I ever had was when my older sister took me fast in my wheelchair while she was roller blading.

I like to play "Ring-Around-the-Rosie."

I like to say '*Good Girl*' and '*You Go Girl*'.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

TOGETHER WE'RE BETTER

Hi, my name is Daniel and I am 4 years old.

I like to play and have fun. My favorite toy is my musical light up keyboard.

My favorite person to play with is anyone -- because I like attention.

I think it is funny when something spins.

The best times I have are on a merry-go-round and in the pool.

A sound or noise that makes me laugh is my sister screaming.

The color that makes me happiest is red.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

TOGETHER WE'RE BETTER

Hi, my name is Vivian and I am 5 years old.

I like to play and have fun with my baby dolls.

My favorite person to play with is my friend, Wayne, because he treats me nice. I also like to play with Dominque.

I think it is funny when other people laugh.

The best time I ever had was when I went to Epcot Center in Florida.

I think the funniest song is "If You're Happy and You Know It Clap Your Hands."

A sound or noise that makes me laugh is people coughing.

The color that makes me happiest is bright yellow like the sun.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Brittany and I am 6 years old.

I like to play and have fun. My favorite toy is my 'Old McDonald' keyboard.

My favorite person to play with is my grandma. She tickles me and makes me laugh.

I think it is funny when I rock in Grandpa's chair by myself. I rock it so hard that I giggle and scare the beejeebers out of my Grandma.

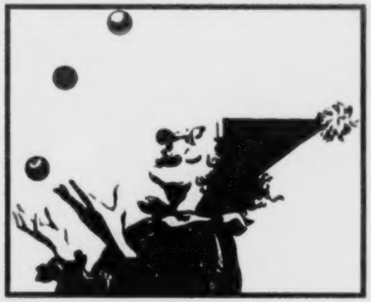
The best time I ever had was going to school and learning signs.

I think the funniest song is "Old McDonald."

A sound that makes me laugh is Grandpa's singing.

The color that makes me happiest is red.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.



6/1999

TOGETHER WE'RE BETTER

Hi, my name is Evan and I am 6 years old.

I like to play and have fun. My favorite toy is my robot that repeats what I say.

My favorite person to play with is my brother. He makes me laugh.

I think it is funny when my brother sings and dances in front of me.

The best time I ever had was when I went on vacation and my brother jumped up and down on my bed. I loved it!!!

I think the funniest song is "Itsy Bitsy Spider".

A sound or noise that makes me laugh is my father's funny sounds he makes in my ears.

The color that makes me happiest is yellow.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

TOGETHER WE'RE BETTER

Hi, my name is David and I am 7 years old.

I like to play and have fun. My favorite toy is "Bouncing Tigger".

My favorite person to play with is Daddy because he wrestles and plays with me like 'one of the guys'!

I think it is funny when I bounce on my trampoline.

The best time I ever had was at Sea World, watching the sea lion show and listening to them.

A sound or noise that makes me laugh is the sound of the vacuum sweeper coming towards me.

The color that makes me happiest is bright yellow!

Play is a child's work . . . children play to learn,
to grow and to experience the world around them.

TOGETHER WE'RE BETTER

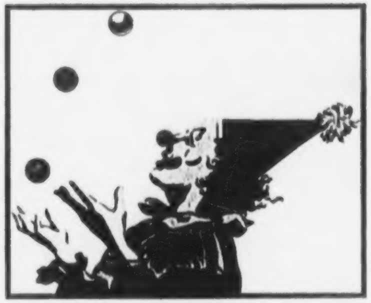
Hi, my name is Jacob and I am 7 years old.

My favorite person to play with is Kathy (my favorite adult playmate!) because she signs well with me and does lots of fun activities with me.

I think it is funny when my brother, Michael, rough houses with me.

The best time I ever had was at Knoebel's Amusement Park.

A favorite toy is my stuffed animal that vibrates and laughs.



Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Alex and I am almost 8 years old.

I like to play and have fun. I like to play in my sandbox.

My favorite person to play with is Allison, my aide at school, because she helps me learn through play.

I think it is funny when someone tickles me or touches my nose.

The best time I ever had was riding 'the whip' at Kennywood Park

I think the funniest song is "Wheels on the Bus."

A sound or noise that makes me laugh is raspberry sounds on my belly.

The color that makes me happiest is red.

**Play is a child's work . . . children play to learn,
to grow and to experience the world around them.**

TOGETHER WE'RE BETTER

Hi, my name is Amberly and I am 8 years old.

I like to play and have fun. My favorite game is "Lucky Ducks", and "Ring Around the Rosie."

My favorite person to play with is Dad - he's so silly!

I think it is funny when I pretend to nap on the couch.

The best time I ever had was inner tubing at Sesame Place.

I think the funniest TV show or song is "Barney."

A sound that makes me laugh is my brother, Matthew, laughing.

The color that makes me happiest is purple.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Billy and I am 8 years old.

I like to play and have fun. My favorite toys are balloons and drums.

My favorite persons to play with are Ashley, Ricky, and Bo because they are rough with me.

I think it is funny when my family acts crazy. (Oh, that's not acting!)

The best time I ever had was swimming with the dolphins.

I think the funniest TV show or song is "Barney."

A sound or noise that makes me laugh is the stereo.

The color that makes me happiest is silver.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Salvatore and I am 8 years old.

I like to play and have fun. My favorite toy/game is my VCR and my Sega video games.

My favorite persons to play with are my sister, Anna, and my cousins, Alex, Thomas, Catherine and Megan.

We go outside and ride bikes and they treat me just like any other kid.

I think it is funny when I am in the bath and make bubbles.

The best time I ever had was at the Special Olympics when I won my medal.

I think the funniest TV show or song is "The Big Comfy Couch 30 Second Tidy."

A sound or noise that makes me laugh is someone burping.

The color that makes me happiest is green.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Rebecca Jean and I am 8 1/2 years old.

The best fun I have is swimming.

My favorite persons to play with are Di Di (my TSS) and my sister, Niki, because they challenge me to do new things.

I think it is funny when I throw the ball for Duchess and she catches it.

The best time I ever had was sitting on my Daddy's lap and sharing his breakfast.

I love music and my uncle has been sending me CD sets of music from the 60's thru the 80's - Rock and Roll to Disco.

A sound or noise that makes me laugh is when my brother Joe pokes my tummy and says "Hoo-Hoo" and makes me laugh.

The colors that make me happiest are yellow and red.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

TOGETHER WE'RE BETTER

Hi, my name is Chavelle (call me Chavella) and I am 10 years old.

I like to play and have fun. My favorite toys are dolls and my favorite game is jump rope.

My favorite person to play with is my twin brother, Shariff. I call him Jerron. He makes me laugh.

I think it is funny when Jerron wrestles with me.

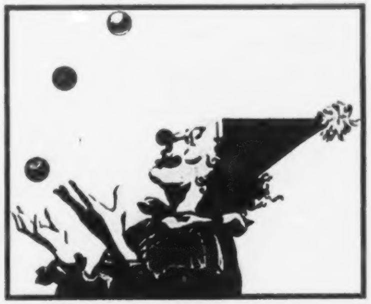
The best time I ever had was when I went to Disney World.

I think the funniest TV show or song is "All That."

A sound or noise that makes me laugh is a scream.

The color that makes me happiest is red.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.



TOGETHER WE'RE BETTER

Hi, my name is Phillip and I am 10 years old.

I like to play and have fun. My favorite toy is my vibrating duck.

My favorite persons to play with are my mommy and daddy. They understand me even though I can't communicate in a conventional way.

I think it is funny when my mommy whispers in my ear, "Mommy loves her baby, bootie, bootie Boo!"

A sound or noise that makes me laugh is my mommy's whispers of silly little notions of love.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Beth and I am 12 years old.

I like to play and have fun. I like to swing.

My favorite person to play with is my nephew, Shane.

I think it is funny when my Dad chases me around the yard.

The best time I ever had was when I went to Kennywood.

I think the funniest TV show or song is "Blues Clues."

A sound or noise that makes me laugh is barking.

The color that makes me happiest is purple.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Brenson and I am 15 years old.

I like to listen to music and sports games.

My favorite person to be with is my sister, Aperna, because she does what I say.

I think it is funny when I wake up everybody in the house by slamming doors.

The best time I ever had was sitting on the beach letting the waves hit my body.

I think the funniest TV show or song is the "Jamie Foxx Show."

The color that makes me happiest is sunlight.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

TOGETHER WE'RE BETTER

Hi, my name is Cristen and I am 17 years old.

I like to play and have fun, especially riding bike and playing basketball.

My favorite person to play with is Kara because she can sign some.

I think it is funny when my cats play.

The best time I ever had was going to Niagara Falls.

I think the funniest TV show or song is "Parent Trap."

A sound or noise that makes me laugh is Mom talking.

The color that makes me happiest is red.

**Play is a child's work . . . children play to learn,
to grow and to experience the world around them.**

TOGETHER WE'RE BETTER

Hi, my name is Bryan and I am 18 years old.

My favorite pasttime is playing with Legos.

My favorite person to play with is Mom because I love her.

I think it is funny when Co-Co bites me.

The best time I have is when I can go swimming in the pool.

I think the funniest TV show is "QVC TV."

A sound or noise that makes me laugh is a big bang!

The color that makes me happiest is red.

Play is a child's work . . . children play to learn, to grow and to experience the world around them.

6/1999

PENNSYLVANIA
DEAFBLIND
PROJECT

6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
phone: 800-360-7282 in PA only
or 717-541-4960
fax: 717-541-4968
web address: www.cisc.k12.pa.us/CISC.pgs/State/DB/DB.html

PA DEAFBLIND PROJECT
C/O CENTRAL INSTRUCTIONAL SUPPORT SYSTEM
6340 FLANK DRIVE, SUITE 600
HARRISBURG, PA 17112-2764

Do you have a child with a hearing loss or who is deaf
AND
who also has a vision loss or is blind?

Is your child at risk for a dual sensory impairment?

If so, perhaps we can help . . . .

PENNSYLVANIA DEAFBLIND PROJECT

WHO ARE WE?

We are the Pennsylvania Deafblind Project. We work with other consultants to support the families, educators and service providers of children who have both visual and auditory impairments.

WHAT CAN WE DO FOR YOU?

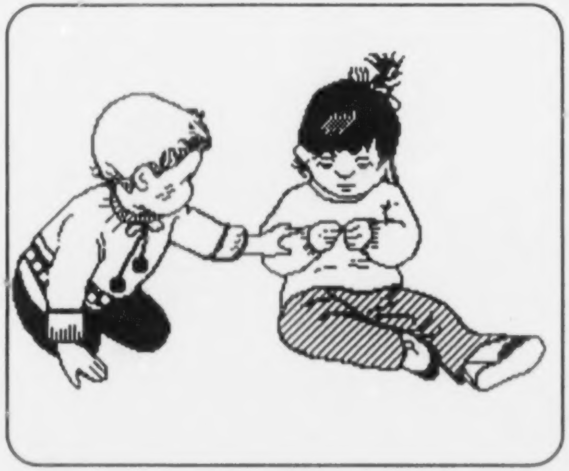
We can talk with you about your concerns regarding the education of your child. We can work with you and your child's team to address your concerns.

WHAT SERVICES ARE AVAILABLE?

We can:

- give you information.
- provide training to teams.
- help you work with agencies.
- link families together

PENNSYLVANIA DEAFBLIND PROJECT



WHO BENEFITS FROM OUR SERVICES?

Families, educators and service providers of children who have both visual and auditory impairments or are at risk. Some children may have additional disabilities.

WHO CAN YOU CONTACT FOR FURTHER INFORMATION?

You can always leave a message for a parent or consultant to return your call by calling:

Nancy Lehr, Project Assistant
Toll free, 24 hours a day
800-360-7282, ext. 3115
e-mail: nlehr@cisc.k12.pa.us

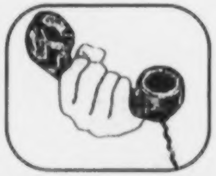
To get in touch with a parent of a child who has visual and auditory impairments, contact:

- Molly Black
  phone: 724-863-1283
  fax: 724-861-0614
  e-mail: 74704.156@compuserve.com

- Stacy Gerlach
  phone: 215-945-7364

- Sue Shaffer
  phone: 717-776-4061
  e-mail: shaffers@dickinson.edu

- Kristy Smith
  phone: 814-833-2739
  e-mail: ksmith@pepper.ncinter.net



To talk with an education consultant, contact:

- Mary Frey
  800-360-7282, ext. 3005 (toll free in PA)
  or 717-541-4960, ext. 3005
  e-mail: mfrey@cisc.k12.pa.us

- Juli Baumgarner
  800-446-5607, ext. 238 (toll free in PA)
  or 724-443-3473, ext. 238
  e-mail: baumgar@wisc.org

- Jeanne Gardier
  800-360-7282, ext. 3132 (toll free in PA)
  or 717-541-4960, ext. 3132
  e-mail: gardierj@ns.neiu.k12.pa.us

STRATEGIES FOR SUCCESSFUL PARTICIPATION IN COMMUNITY ACTIVITIES

May 1997

Pennsylvania Deafblind Project
6340 Flank Drive, Suite 600
Harrisburg, PA 17112-2764
phone: 717-541-4960
e-mail: http://www.cisc.k12.pa.us

MANY FAMILIES FEEL THAT SUCCESSFUL PARTICIPATION IN ANY ACTIVITY, PROGRAM, OR ORGANIZATION DEPENDS ON THE ATTITUDE, WILLINGNESS, AND COMMITMENT OF THE COMMUNITY PERSON HAVING THE MOST DIRECT CONTACT WITH THEIR CHILD.

SPECIAL THANKS TO:

The Building Community Resources Project
Orelena Hawks Puckett Institute
Asheville, NC
and
Allegheny-Singer Research Institute
Pittsburgh, PA

and

the Pennsylvania families
for their contributions of ideas
for this booklet.

"Start young
so people will get to know your kids.
The more people get to know you
and your family,
the more comfortable
they will be having you there."

"You can't give up.
Keep trying.
Keep calling.
Just keep on keeping on.
You'll get no's, but
somewhere you'll get a yes."

Mother receives help for transporting children to medical appointments by placing advertisement in local newspaper.

A friend of the family who works as a lifeguard at a private residential pool makes arrangements to use the pool for private swim lessons.

Parents and older children volunteer to push children in wheelchairs or kidkarts so they can attend field trips and camps.

Young child participates in a community's bike parade with the aid of a parent using a push bar attached to the child's tricycle.

Parent, physical therapist, and karate instructor work as a team to provide a successful sporting opportunity for a child.

During a neighborhood July 4th picnic, a mom suggests that her son play "back-up" catcher for the softball game enabling him to be involved in the activity.

Beeper balls and a buddy using voice commands enhances a child's success while playing baseball.

Child experiences success at community nature reserve because family feels welcomed, known, and appreciated through their volunteer contributions.

Mom enrolls her toddler in playgroup where teacher is familiar with the family through older children who attend the same elementary school.

Family feels that son's community involvement is a positive reflection of the extent of their connections in the community.

Grandmother searches for ways to acquaint her grandchild with other children in the neighborhood during a typical day.

Family calls parks to see if cabins and swimming pools are accessible for their child before they go camping.

Mother gets trading cards made of her son -- kind of like baseball cards -- and hands them out to kids in the neighborhood, helping her son become more known. He joins the local T-ball team.

Teacher contacts local scout leader and one of the scouts agrees to be an aide in a Sunday school class as part of his Eagle Scout project.

Families talk to friends, neighbors, and acquaintances to find out which programs, schools, or activities in their community have provided positive experiences for their children and families.

Young children participate with a parent in a variety of community activities that routinely involve parents such as library story time, gymnastic classes, water babies, or toddler groups experiences.

Young boy with a visual impairment learns to ice skate through the family's weekly participation in family skating night.

Parent volunteers to be an assistant sports coach or a scout leader so their child will feel comfortable participating in the activity.

Extra adult support, i.e., relative, neighbor, friend, or babysitter participates with a large family in community events such as festivals, concerts at the park, or visiting museums.

Camp directors and parents contact local high school volunteer clubs and community college programs to enlist student volunteers to support children in various summer day camps and swimming lessons.

Young teen joins the cheerleading squad. Family sets up her communication board with the cheers, decorates her wheelchair with the school colors, gets her a uniform. They attend practice sessions to assist their child in boosting school spirit at the local athletic association.

Parents feel their child has had many successful community experiences because they present the whole story about him, give a complete picture and not a limited picture focusing on the special needs.

Financial support for various programs/ activities has been obtained through scholarship funding, working out payment plans, bartering services, fund raising by the family or support group; organizations, and the use of family support services funds.

Mother contacts adults who have disabilities like her child to find out what kind of trips they enjoyed when they were young. She finds alumni and older mentors who share trips with her child and family.

Teachers and coaches use short segments of information followed by positive reinforcement which helps children follow sequential directions.

Child with a visual impairment participates in the library's story time coloring activity by having the outline of the picture traced with glue and then being left to dry so he could feel it while coloring.

Some families choose not to reveal their child's disability during the initial contact with a community resource. After a relationship has been established and a parental decision made about the child's prospective enrollment in a program, the amount of information provided varies depending on the activity involved.

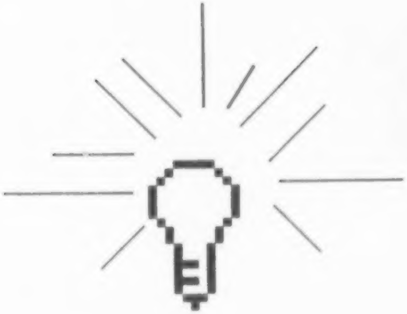
Family signs daughter up for Girl Scouts, teaches them sign language so they can interact with her.

Family enjoys participation in community 5K walk/runs with use of a special needs jog stroller.

Single parent family regularly sits with another family at church so older sibling feels comfortable when mother needs to leave with younger child.

Therapist unobstrusively joins a child's structured play activity at the school playground, horseback riding, or swim class to provide therapy in a more natural setting.

Parent contacts the director of special education at a local university to see if a student would be interested in an internship at her daughter's preschool.



Here are some good ideas we caught...

Always keep in mind that your special needs child is a child FIRST. Have fun with him/her as your child. The special needs come second.

Shari Jarrell
Mother of Jacob

You know how people stare at your child? I've been considering making up collector cards with his picture, name, diagnosis, etc. , and handing them out to people; then, maybe they won't stare anymore.

Stacy Gerlach
Mother of Billy

When we need to go to the hospital, I take along a letter stating all about my child 's condition and all about his medical history. That way, hospital personnel will not always be asking the same questions over and over again.

Barbara Gambino
Mother of Salvatore

I use fabric paint, magnets, ribbons, and contact paper to decorate wheelchairs, trays, walkers and canes. It's also great to tie bells to wheelchair wheels.

Charlene Zink

SENSORY ACCOMMODATIONS

- Smoke alarms -- problems with auditory alarms. Contact Smith Kettlewell
- Using resources for the deaf community:
  - -- closed captioning
  - -- TTYs
- Differences in O & M training for students; "Hand in Hand" -- can it be loaned
- Who to talk to about EI services?
  - -- PEN
  - -- FFEIS
- CCI canine companions for independence -- get contact number
- Cochlear implants update:
  - -- cautions on static electricity
  - -- can be fitted from two years
  - -- need for training

(Hints as developed from sessions at the weekend itself)

COMMUNICATION / ASSISTIVE TECHNOLOGY

- have a back-up system
- identify alternative/new funding sources
- start as early as possible; don't wait for the "equipment"
- need agreement on features of assistive technology
- use action plan(s) to keep on track and to make sure there is agreement
- establish relationships with manufacturers
- try short-term loan before buying (make sure it works at home and school)

Visiting Nurse Associations can be resource for respite care.

(Hints as developed from sessions at the weekend itself)

When Sammy was younger, every now and then I would wear my favorite perfume while holding her close. And when I left the house, I would ALWAYS wear the perfume so that she would know Mommy was near. Sammy's five therapists would also wear their favorite perfume during visits. Sammy is now 2-1/2 years old and knows all of us without our favorite scent. But we sure did smell good for those two years!!

Sandy Parry
Samantha's Mother

Place Velco strips on shoestrings to keep shoes in pairs, then place and store in recycled plastic bread bags. These are great at home and for traveling for children with a visual impairment, as well as an environmental aid.

The Family of
Chiffon Jackson

SELF CARE

- record cues on a tape recorder to tell next tasks to be done
- discern environmental cues
- develop a list of responsibilities
- use touch cues
- maintain conversation of social things throughout dressing/grooming
- decide on the "carrot" at the completion of the task
- take the "fun" out of routine tasks and be "matter of fact"
- teach self care routine in structured manner
- be specific on starting and stopping times

(Hints as developed from sessions at the weekend itself)

SUGGESTIONS TO CONSIDER WITH A CHILD WHO HAS SLEEP PROBLEMS

- no nap
- massage hand/foot
- aromas that relax
- book -- "Solve Your Child's Sleep Problems" by Richard Ferver
- deep pressure
- evening walk
- rocking
- vibrating pillows
- water bed
- look at feeding time
- set routine
- sleep room only for sleeping
- establish boundaries around the bed
- how much sleep does your child need?
- create a safe environment for night wake hours
- investigate the eating disorder

(Hints as developed from sessions at the weekend itself)

> ***We use laminated paper (can also special order for labelers) to Braille items such as the microware, so that John can read the Braille and we can read the print.***
>
> ***Ida Holcomb***
> ***Mother to John***

With two four-year-old girls (only three months age difference), eating has become a competition to see who can clean their plate first. We also make a competition on washing faces, brushing teeth, and combing hair.

C. J. Carroll
Katy Molyneaux's Mom

✿ ✿ ✿ ✿ ✿ ✿ ✿

Videotape your child doing various activities, i.e., mealtimes, sibling play, family outings, and "activities of daily living" skills. This will serve as a "resume" for your child.

Cynthia Jackson-Glenn
Mother of Nafisa Zuri

I've been unsuccessful in teaching John to cup water in his hands for facewashing. Now we use Noxema pads in between showers.

Ida Holcomb
John's Mom

We bought a medic alert bracelet for Sean with our names, address, phone number, and stating the fact that Sean is deaf -- so we can be contacted if he gets separated or in an accident.

George McHale
Sean's dad

* * * * *

For more tactile interest, I sew buttons and patches on Katy's playclothes. She calls these her funny pants.

C. J. Carroll
Katy Molyneaux's mom

* * * * *

At nap time, I pull down the shades in Rebecca's room. Then when she awakens and before I get her up, I roll up the shades. This is a "sign" to her that it is time to get up. She usually rises with a smile and a "hi".

Jean Weaver
Mother to Rebecca

We keep Access information in the computer along with daily medications, amounts, dosages, and phone numbers of the specialists. We print a copy and give to the receptionist when signing in. It saves time and new information can simply be added to the child's record.

Charlene Zink

When potty training, I take regular underwear and put it over his disposable diaper when we are going out. That way, he still thinks he is a big boy and he stays dry.

Jill Fitch
Mother of Bryan

Check to see if an inappropriate behavior has an underlying medical cause. There are many causes for behavior, such as the need to communicate, the need to interact and play, and physical causes. Look at all the potential reasons for a behavior, discuss your thoughts with others, and come up with a plan that everyone can use.

Molly Black
Mother of Alex Black

When Christopher, who is non-mobile, began to outgrow his crib at age 2-1/2, we got him a daybed with simple wooden sides. The daybed can be turned around so the open side is against a wall. Two sets of bumper pads fit nicely around the perimeter. The extra height of a daybed makes it easier for dressing and changing Christopher -- not as much bending over.

Christopher's Mother, Alisa Griffith

✿ ✿ ✿ ✿ ✿ ✿ ✿ ✿

If possible, videotape the progress of your child. This could be your best advocate.

Nasrat Ghattas
Mother of Nada

✿ ✿ ✿ ✿ ✿ ✿ ✿ ✿

When children stop and stare at Timmy, I use the chance to introduce Timmy and ask the child's name. I try to get a conversation going. The child usually asks questions about Timmy that help the child to better understand Timmy's disabilities. Timmy is very social and loves meeting new people. I try to take an occasional rude and hurtful situation and turn it into a positive experience.

Shelly Zabroske
Timothy's Mommy

We travel from time to time -- whether by land, sea or air. We always need to be prepared. I keep a large zip-lock freezer bag filled with a small bottle of seizure medicine or any other meds CJ requires, along with feed tubes, a can of Pediasure (so she can eat), and a mickey button kit (if there's an emergency and the hospital doesn't have it, I do). I also carry a diaper or two in this bag. So even if we are on a day trip and we're gone longer than expected, she can eat and take meds on time; same thing if we are stuck at the airport -- I don't need to panic.

Andrea Cain Johnson

I put my son, George, in a large clothesbasket when we are in the basement near a lot of "no-no's" . I give him a few toys and he's occcupied while I load and empty the washer and dryer.

Marcella Zielinski

INFORMATION UPDATE

from

Hand in Hand in Hand: A Partnership Serving
Families, Educators, And Service Providers
of Children and Youth Who Are Deafblind

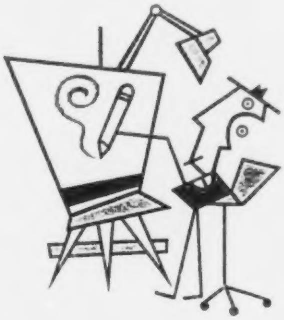
Issue 9
Fall 1999

On behalf of the Pennsylvania Deafblind Project, we hope you have had a great start to the new year. Beginning in October, our name has been expanded to "Hand in Hand in Hand: A Partnership Serving Families, Educators, And Service Providers of Children and Youth Who Are Deafblind." If we can partner with you and other members of your child's team for training and technical assistance (help with child's program, goals, communication, etc.), please contact the project. You can call, write, fax, or email Nancy Lehr, who will refer your request to an education consultant or a family liaison.

We were recently awarded funding for two grant proposals: "Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth who are Deafblind" and a matchmaker grant involving paraprofessionals. These projects will be funded for four years, from October 1, 1999, through September 30, 2003. We will continue to provide training and technical assistance to families, educators, and service providers of children and youth who are deafblind, as well as begin some new and exciting efforts.

Status Report or "State of the Art"

To give you a sense of the services provided through the project, here are some data and facts from the past year.



Census: We must keep an ongoing record of changes in the population of children and youth who are deafblind, or at-risk for deafblindness in PA. Last year, 40 children were newly identified. Currently, there are over 400 children and youth in PA on the census.

Personnel: Jeanne Beck-Gardier, a vision consultant from IU 19, joined the Project on a part-time basis. We have benefited from her many years of experience in the field of vision education, and her presence in the northeastern corner of PA. Susan Shaffer, a parent of a child with deafblindness, joined us as a family liaison. She provides information and support to other family members, and serves in multiple capacities.

Inside this issue:

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Upcoming Teleconferences 4

Family and Educator Learning Awards: Thirty-two awards assisted families and educators in meeting the needs of children and youth who are deafblind. For example, the Deafblind Project:

- Sponsored 3 parents, 2 children for PA Parent Involvement Workshop.
- Sponsored 2 parents for NTAC/NFADB Parent Workshop.
- Sponsored 2 parents, 1 child for National CHARGE Workshop.
- Sponsored 6 families' travel costs for Family Learning Days/Weekends.
- Provided 8 "Hand in Hand" or "INSITE" curriculums to families, educators.
- Provided 3 "COACH" books and 8 "Collaborative IE Writing Handbooks" to study-group members

Training and Technical Assistance: The Project continues to partner with teams to improve educational outcomes for children and youth who are deafblind. In the past year, the Deafblind Project:

- Provided 71 workshops to 982 educators, 45 paraeducators, 98 parents.
- Provided onsite assistance to 126 educators, 37 paraeducators, 24 parents.
- Consulted by phone (45 min. +) with 23 educators & paraeducators, 16 parents.
- Developed and disseminated Information Updates to 590 parents & 2502 administrators, educators & paraeducators.
- Disseminated and/or loaned resources and/or materials to 7352 persons.

Advisory Council

The Advisory Council for the Deafblind Project, comprised of parents, consumers, and educators, met in September. A very productive meeting resulted in plans to develop specific materials to share with families and educators of newly identified children, and to provide valuable feedback to the Project. Contact us if you are interested in joining the Council. We meet once a year in Harrisburg, and communicate via telephone conference calls three times a year. Current council members are: Molly Black, Kathryn Daugherty, Ginny Duncan, Sherry Fahs, Stacy Gerlach, Kathleen Huebner, Andrea Johnson, Bernadette Kappen, Susan Kershman, Rich McGann, Anthony Murphy, Pamela Porter, Sue Shaffer, Ava Shaffer, and Randi Shelton, and Project Staff.

Study Groups

Three groups of family members, educators, and other team members have been participating in "study groups." Our study groups (4 to 6 people each) have met on telephone conference calls to review and apply information to their children or students. Recent topics have included the collaborative process to develop IEPs, educational needs of students who are deafblind, and orientation and mobility techniques. A family liaison and/or an educator coordinate the conference calls, sponsored by the Deafblind Project. Study groups are a wonderful opportunity to learn something new, confirm that you are "on the right track," speak with others about your child or student, and bounce around ideas. If you are interested in joining or starting a study group related to deafblind education, please contact the Project. Current groups are held on one Tuesday or Thursday per month from 7:00 to 8:00 p.m.

Focus Groups

Families, educators, and service providers of children who are deafblind can benefit from linking with others who may be experiencing similar challenges and successes. To link these individuals together, the Project will sponsor a series of focus group telephone conference calls. The first will be related to Usher Syndrome. Two times are offered to accommodate your schedule. The date is December 14, 1999; the times are 10:45 - 11:45 a.m., and 6:45 - 7:45 p.m. To reserve your place for the focus group, please contact the Project by December 1. Participants must be family members, educators, or service providers of children with Usher Syndrome. The goals of the telephone conference call will include information sharing and other topics as decided by the participants.

Topics of upcoming focus groups include CHARGE, cochlear implants, and other ideas as determined by you. Please give us your suggestions for focus group topics. You may complete and mail the form below, or call, email or fax Nancy.

Lending Library

The Project has a number of new books and videotapes available for loan. Topics include communication, inclusion, transition to adult life, Usher Syndrome, IEP planning, teams, paraprofessionals, literacy, and diversity. Call Nancy for more information.

✂

Return to:
Nancy Lehr
Hand in Hand in Hand
6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2793
Phone: 800-360-7282, ext. 3115; Fax: 717-541-4968; Email: nlehr@cisc.k12.pa.us

Name ______________________________

Address ______________________________

Phone Number ______________ Best time to call ______________

I would like more information about:

______ Study Groups
______ Dec. 14, 1999, Usher Syndrome Focus Group
______ Technical Assistance from the Deafblind Project. Please describe your needs ______________

____

My suggestions for future focus group topics include: ______________________________

____

Upcoming Teleconferences

Teleconferences are programs which are broadcast live from the PA Department of Education Distance Learning Center, and are also available on videotape after the broadcast. Two programs in January would especially be helpful to families, educators, and service providers of children and youth who are deafblind.

January 14, 2000, from 9:00 a.m. - 3:30 p.m. "Teaching Students with Visual Impairments: Effective Process and Practice"

The changing roles of the teacher of the visually impaired, family participation in the educational process, and effective strategies for a team approach will be explored. Please contact the Distance Learning Center (800-236-5293 or 724-443-7488) to register. For content information, contact Debby Oppel Holzapfel (800-446-5607 ext. 222 or 724-443-7821 ext. 222) or Diane P. Wormsley (215-780-1366).

January 19, 2000, from 9:00 a.m. - 3:00 p.m. "COACH: Choosing Options and Accommodations for Children with Disabilities"

An overview of a systematic process for identifying and prioritizing educational needs which are linked to families' valued life outcomes will be presented. Please contact the Distance Learning Center (800-236-5293 or 724-443-7488) to register. For content information, contact Juli Baumgarner (ext. 238) or Patty Pasqua (ext. 243) at 800-446-5607 or 724-443-7821.

Save these Dates

June 23-25, 2000 — Family Learning Weekend
August 7-9, 2000 — Summer Institute on Deafblindness

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Latest information from Hand in Hand in Hand

UPDATE ON THE PENNSYLVANIA DEAFBLIND PROJECT

Pennsylvania Deafblind Project

Spring 1999
Issue 8

Special points of interest:

- ☺ Conferences
- ☺ Family Learning Retreat
- ☺ Study Groups

We Would Love To Hear From You!

Spring and summer are just around the corner, and there are many items that we wish to share with you, as you plan for the next few months.

The PA Deafblind Project will end a four-year grant cycle in September 1999. We are busy preparing a federal grant proposal to help us continue to provide training and technical assistance for the next four years.

We welcome any ideas, activities, or suggestions to address current or future needs of those providing early intervention services and/or education to children and youth (birth through age 21) with deafblindness to be considered for inclusion in this proposal.

If you have any comments, or would like to share with us how the Pennsylvania Deafblind Project has been of benefit to you, we would welcome any feedback from you. In order for your feedback to accompany our grant proposal, we would need to receive your correspondence before **April 19, 1999**. Please mail correspondence to the attention of Mary R. Frey at the Project's address.

Training Opportunities

There are numerous training opportunities scheduled for the next few months. We would like to share information with you in this update about activities sponsored by the Pennsylvania Deafblind Project, as well as workshops and conferences offered by others.

Families may contact the project if they are interested in attending these activities, as we may be able to support some of the related costs.

Inside this issue:

INSITE Materials Available On Loan 2
Identification 2
Training & Family Opportunities in PA 3
Other Opportunities in PA 4
Help for Parents 4
National Conferences 5
Project Web Site 6

Insite Materials Available As "Learning Awards"

We have a limited number of *INSITE* curriculum sets available for loan to families, educators, and service providers. The curriculum is appropriate for children from birth to eight years of age, who have multiple and sensory impairments, including deafblindness. In order to make the loan permanent, we ask that you update us on how you have used the materials six months and one year after receiving them.

The curriculum set includes Volumes I and II of the *INSITE* curriculum, the *INSITE Developmental Checklist* and *Instruction Manual*, and home visit *Topic Summary Sheets*. If you would like to borrow the curriculum set, please call the Deafblind Project to request a "Learning Award for the INSITE Materials."

Identification of Children and Youth Who Are Deafblind or At-Risk for Deafblindness

We are in the process of receiving updates from families, school districts, intermediate units, and early intervention agencies on children and youth who are deafblind, or at-risk for deafblindness. We thank you for your assistance in this endeavor, as it helps us plan our activities by identifying potential needs, allows us to contact families and service providers directly, and also is a requirement of our federal grant activities.

Currently, we have 392 infants, toddlers, children, and young adults listed on the PA deafblind census. To date, we have identified an additional 37 children and youth in Pennsylvania through this process this year. Please feel free to contact us with new updates or questions about this process.

Currently...

Project Staff continues to assist teams in meeting the needs of children and youth who are deafblind by providing individualized support to those teams.

> **"I learned so much from Terry (Rafalowski Welch) during the literacy videoconference about how to use books with young children who have vision and hearing impairments."**

Contact the Project to schedule assistance and/or training. PA Deafblind Project, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764. Please feel free to call Nancy Lehr, our project assistant, who will respond to your questions, or put you in touch with an education consultant or family liaison. Contact Nancy Lehr at 1.800.360.7282 ext. 3115 (PA only) or 717.541.4968 ext. 3115.

Training and Family Involvement Opportunities Sponsored by the PA Deafblind Project

Please note that while we offer specific family activities, families are welcome to attend any workshop or activity offered by the Project (e.g., workshops for teachers).

June 25-27, 1999 (Friday, 6:00 PM - Sunday, noon):
The 1999 PA Deafblind Project Annual Family Learning Retreat "Together We're Better: Learning Through Play and Humor" is scheduled at the Harrisburg/Hershey Holiday Inn. This retreat is for families who have children (ages birth through 21 years of age) who are deafblind, or are at-risk for deafblindness.

Family Learning Retreat

June 25, 1999 (Friday 9:00 AM - 4:30 PM)
"Shared Experiences: Increasing Literacy and Communication Opportunities for Children with Deafblindness," is scheduled at the Harrisburg/Hershey Holiday Inn. Terry Rafalowski Welch is returning to PA to be the facilitator of this workshop which is open to educators, paraprofessionals, and parents. Part of the day will be spent making experience and object storybooks. (This workshop is one of the options for the fourth "Quarterly Institute: Literacy for Students with Sensory Impairments" series).

August 9 - 13, 1999 (Monday - Friday, 8:30 AM - 4:30 PM)
"Deafblind Education: A Path to Communication, Positive Behavior Support and Instruction," is scheduled at the Penn Stater Conference Center, State College. This week long accredited course has four instructors: Stephanie McFarland, AZ, Anne Malatchi, VA, Susan Edelman, VT, Chigee Cloninger, VT. Instructors are university personnel and well-known in the field of deafblind education.

> **"On the study group phone calls, I enjoy the chance to talk about my child with other parents who understand."**

Ongoing Study Groups
Parents, educators, service providers, and others may participate in ongoing study groups, which meet monthly, via a telephone conference call in order to discuss resource materials and application to their child or student. New participants may join at any time, or form their own study group. The Project supports groups by sponsoring the conference calls and providing resource materials and facilitators. Currently, there are three study groups: two focus on communication, orientation and mobility; the other focuses on collaborative IEPs.

Read and talk

PA Deafblind Project
Education Consultants: Juli Baumgarner, Mary Frey, Jeanne Gardier
Family Liaisons: Molly Black, Stacy Gerlach, Sue Shaffer
Project Assistant: Nancy Lehr

Other Opportunities in Pennsylvania

Intermediate units and school districts may offer summer courses or sponsor summer camps. Call your intermediate unit or school district to inquire about possible offerings.

April 28-30, 1999: "Collaboration: A Vision for the Future," Grantville, PA. This Spring Conference for Service Providers in the Field of Visual Impairment covers a multitude of topics related to individuals with visual impairment. Contact Vince McVeigh at Delaware County IU 25, 610.543.7633

May 15, 1999: PA Cornelia de Lange Syndrome Family Gathering, Somerset, PA. Contact Molly Black at 724.863.1283 for more information.

May 20-21, 1999: "Bringing Sound to Life: Principles and Practices of Cochlear Implant Rehabilitation." This teleconference will be available at several downlink sites, and on videotape afterwards. The teleconference will provide participants with a foundation of information and strategies to implement a cochlear implant rehabilitation program for children 2-17 years of age. Call the Distance Learning Center to register at 800.236.5293 (PA only) or 724.443.7488.

Two children have been identified on the deafblind census with Cornelia De Lange Syndrome.

June 22-23, 1999: "Professional Summer Workshop," Overbrook School for the Blind, Philadelphia, PA. Overbrook School for the Blind is offering a workshop for teachers in need of basic information about young children who are visually impaired. There is a small fee. Contact Sandy Finkel from Overbrook at 215.877.0313, ext. 319 for more information.

June 21-25, 1999: "TEAMS: Together Exploring All My Senses," Overbrook School for the Blind, Philadelphia, PA. Overbrook School for the Blind is offering a workshop that will help parents learn specialized techniques to enhance their children's growth and development. The workshop is for parents and their children with visual impairments between the ages of birth and three years. There is no cost to families for this workshop. Contact Cassandra Giardina from Overbrook at 215.877.0313 for more information.

Help for Parents

The "Exceptional Parent's 1999 Resource Guide" is also available on the World Wide Web at http://www.eparent.com The Guide provides free information, expert advice, information exchanges and resources for everything from A-Beta-Lipoproteinemia to Ziehen-Oppenheim Disease. Featured on the site currently is an article from Exceptional Parent Magazine entitled "Obtaining Funding for Medical Equipment."

National Conferences

The following information is about national conferences which may be of interest to you.

****If a family is interested in attending, you may contact the PA Deafblind Project to request a "FAMILY LEARNING AWARD APPLICATION" to help defray some of the expenses. Please contact the PA Deafblind Project as soon as possible if interested.*

June 24-27, 1999: 20th Annual International Conference of the Cornelia de Lange Syndrome Foundation "Everyone's A Star Deep in the Heart of Texas" at the Doubletree Hotel, Dallas, Texas. Cornelia de Lange Syndrome (CdLS) is a rare birth defect suspected to be genetic in origin and which causes children to develop slowly mentally and physically.

This conference will bring families, friends, professionals, and the nation's foremost experts in their fields together to share the latest information available on this syndrome. Free medical consultations will be available for children with CdLS. Contact: Gretchen Vakiener, Conference Coordinator, CdLS Foundation, 1.800.753.CdLS; cdlsintl@iconn.net Web page: http://www.cdlsoutreach.org

July 23-25, 1999: 4th International CHARGE Syndrome Conference, "CHARGE into the New Millennium," at the Sheraton Crown Hotel, Houston, Texas. Early registration is urged so that childcare, interpreting, and nursing care can be planned. Contact: 1.800.442.7604 for families; 573.499.4964 for professionals or mnorbury@mail.coin.missouri.edu

Pennsylvania has identified 18 children between birth and age 21 who have CHARGE Syndrome.

May 4-7, 2000: International Parent to Parent Conference 2000 at the Hilton Casino and Resort, Reno, Nevada. This bi-annual conference is one of the largest conference of parents and families in the U.S. Topics will include: Strategies for Addressing Challenges of Diversity and Culture, Legal Rights and the System, Professional Relationships and Partnerships, Community Resources and Collaborative and Innovative Programs and Strategies. Contact: Cheryl Dinnell, NV Parent Network Coordinator, UNR-REPC/285, Reno, NV 89557; 720.784.4921, ext. 2352 or Cdinnell@scs.unr.edu

> **"What a wonderful chance to be able to go to the Family Involvement Conference last fall in the Poconos and learn what is happening with families and schools all over PA."**

We're on the web!
http://www.cisc.k12.
pa.us

*** For Your Information ***

The main office of the PA Deafblind Project is located at the Central Instructional Support Center (CISC) in Harrisburg. The webpage for the PA Deafblind Project can be accessed through the CISC webpage at http://www.cisc.k12.pa.us.

Although this website is undergoing heavy reconstruction, the Project currently has information, resources, links to other sites related to deafblindness, and e-mail to Project staff. It is also possible to link to the text of IDEA '97 and the recently released rules and regulations that apply to IDEA '97 via the CISC webpage.

Pennsylvania Deafblind Project

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Latest information
from the Pennsylvania Deafblind Project.

The Pennsylvania Deafblind Project

serving students with dual sensory impairments

Information Update

Issue No. 7

Fall 1998

The purpose of this Information Update is to describe project activities and to share ideas. We encourage you to copy and share information, but please provide appropriate citations.

ANNUAL PERFORMANCE REPORT

The Deafblind Project, as part of its federal grant requirements, must compile and submit an annual performance report. This year, Pennsylvania received a positive response from the federal grants officer for the report.

> "The document reflected excellent progress of the project for children with deafblindness. The document was also impressive with its layout, color graphics, and informational inserts. Good job to all staff."

A partial copy will soon be placed on the Project's web page for your reading pleasure -- *http://www.cisc.k12.pa.us/CISC.pgs/State/DB/DB.html.*

TRANSITION

The Project is interviewing the parents of all youth identified as deafblind between the ages of 16 and 21 to gather information about their transition process. Parents and their children will be given information about "Community and State Transition Team Partnerships," a national model which has been successfully used in Pennsylvania for the past seven years. Families and the transition team for each child will be invited to become part of the partnership model.

Mary Frey from the Project along with a parent, a consumer, a community team member (Anita Iurlano) and a state team member (Dael Cohen) were part of the National Cohort Workshop to Expand Community and State Transition Team Partnerships held this summer in Kansas City, Missouri. They shared and learned strategies for success and pitfalls to avoid from other states involved in the partnership model. For more information, contact the Project.

RESOURCES

There are a number of new resources available on loan from the Project. Please feel free to call and discuss your particular request with an education consultant.

QUARTERLY INSTITUTES

A series of workshops on literacy, communication, and instructional programming for students with sensory impairments was launched in August, and will continue throughout this school year. The Pennsylvania Department of Education, the Instructional Support System of Pennsylvania, and the PA Deafblind Project are providing this statewide training in an effort to enhance services for students with sensory impairments.

Participants in the first Quarterly Institute will meet three more times (November, February, June) via videoconference and in small groups to continue learning about literacy, communication, and instructional programming for students with sensory impairments. For more information, contact the Project.

ENCLOSED WITH THIS ISSUE:

- Talking the Language . . .
- Zenola's Story
- Tips for Students with Usher's
- "First Glance" (PA Dept. of Ed.)
- Q & A About the Project

Welcome

Jeanne Gardier: Newly-hired part time education consultant (2 days per week)
Sue Shaffer: New additional parent contact (see mini-profile in this issue)

CHARGE CONFERENCE

Pennsylvania parents of children with CHARGE Syndrome were invited to the Mid-Atlantic Charge Syndrome meeting held in Maryland in August. Up-to-date genetic information and the implications of the physical complications of the syndrome were shared. A speaker from The Kennedy-Kreiger Feeding Clinic showed videotapes of pediatric feeding disorders evaluations and various treatments.

One mom told her story about her daughter who has CHARGE and gave many great strategies about raising a child with this syndrome. This was followed by an education consultant giving a bit of history regarding the educational laws and emphasizing parents' choices within the law. Although the number of participants was small, a community of support was built during the weekend. Materials from the conference are being forwarded to those families whose children are identified on the PA deafblind census with CHARGE Syndrome.

ANNUAL CENSUS

The Project sent out a one-page sheet per child identified on the annual federal census in 1997-1998 to reporting agencies and schools. This sheet is a summary of the information provided and can be placed in the child's records for future reference. Plans are to mail out the 1998-1999 census forms in early January for completion by late February. This will give educators time to update any functional vision and/or hearing assessments so that information is current for the upcoming census. Census information is also used to plan future training and workshops.

INCLUSION SUMMER LEADERSHIP INSTITUTE

Molly Black, family consultant, and Mary Frey, education consultant of the Project, participated in an Inclusion Summer Leadership Institute held at Duquesne University. Much information was shared and demonstrated by the speakers, Jack Pearpoint and Marsha Forrest, regarding how to build an inclusive community.

"Most of us are more capable than some of us but none of us are as capable as all of us." (Tom Wilson) This quote was exemplified throughout the workshop as participants learned how to do Circles, MAPs, and PATHs -- all tools to assist in building the community connections and friendships critical for all. Participants discussed how to build a network of supports to assist in accomplishing life goals, important to all but crucial for children with special needs. More information is available from the Project.

PARENT WORKSHOP

Juli Baumgarner from the Project and four Pennsylvania parents joined 76 other parents at a national workshop, "Going for the Best" (sponsored by the National Family Association for the Deaf-Blind and the National Technical Assistance Consortium for Children and Young Adults with Deaf-Blindness) in St. Louis, Missouri.

The parents, representing the diversity of ages and capabilities in children and youth who are deafblind, generated a list of practices entitled "Parents' Perspectives on Behavior, Communication and Instructional Strategies." These practices are those identified by parents as critical in the education of their child. This list will soon be available upon request from the Deafblind Project, and will be distributed in October to service providers and families of children and youth who are deafblind.

"Most of us are more capable than some of us but none of us are as capable as all of us."
Tom Wilson

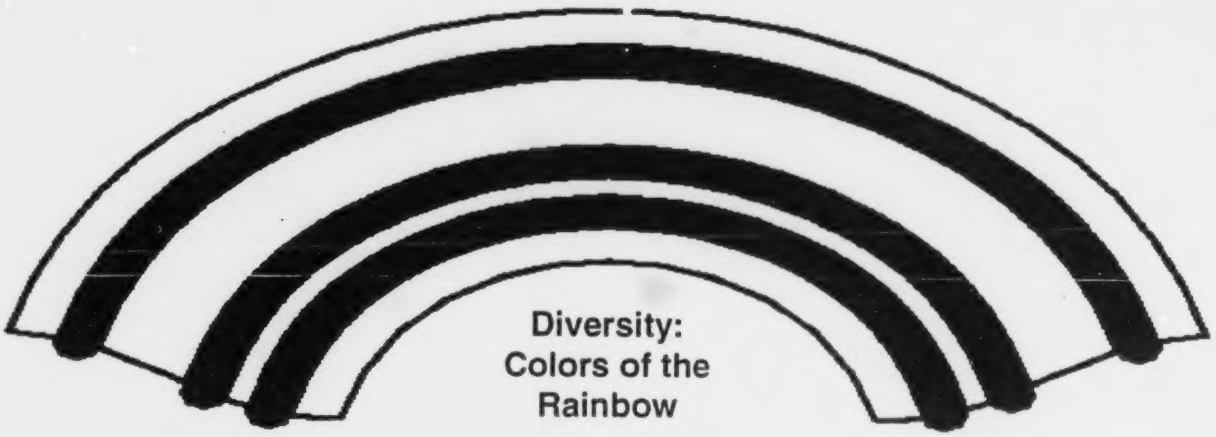
INTRODUCING SUE SHAFFER

Sue has recently "come on board" as a parent contact for the Deafblind Project. She lives in Cumberland County with her family, Amber (seven years), Daniel (four years), and husband, Steve. Sue's son, Daniel has both visual and hearing impairments due to CHARGE Association. Daniel will hopefully be the recipient of a cochlear implant in November. Among Sue's many involvements are parent member of the Local Interagency Coordinating Council and a team member of a technical assistance grant which is researching early intervention processes. For the Project, she is currently contacting parents whose child has had a cochlear implant to get their perspectives on the process. To get in touch with Sue, you may leave a message for her with Nancy, Project Assistant, at 800-360-7282, ext. 3115, or e-mail Sue at *shaffers@dickinson.edu*.

ANNUAL PROJECT DIRECTORS MEETING

In mid-October, Project staff will be participating in and presenting at the Annual Project Directors Meeting for Deafblind in Arlington, VA.

September 30, 1999, is the ending date for the current four-year grant period. This grant money plus in-kind services from the Instructional Support System of Pennsylvania have provided the training and technical assistance activities to those working in PA with children who are deafblind from birth through age 21.



Diversity: Colors of the Rainbow

FAMILY LEARNING RETREAT

The annual statewide Family Learning Retreat, "Diversity: Colors of the Rainbow," was held at the end of June in Grantville. Many wonderful activities were held for siblings, children with deafblindness, and their parents or grandparents. Comments from several of the parents were:

"What I liked best at the retreat was a chance to relax and get away with other families and professionals who really understand. The IEP information was of most value because I will be having an IEP yearly for the next 14 years. I am learning that sometimes taking one day at a time is fine, but there is a future with bigger and better things".

"This was a great weekend. Being able to talk to other families with similar situations helped us understand what we need to provide for our child. Being together, learning more, achieving new skills and perspectives, talking with old and new friends was what I liked best about the weekend. I take a lot of the information home and put it to practical use."

"I enjoyed the pace of the conference. Enough time was given to get where we needed to be. I liked the opportunity to network and the informal, but structured, discussion sessions plus networking with professionals as well as other parents."

Omar and Kerry Kirkland, young adults who are deafblind, shared their experiences with the families regarding using access technology. Parents and children had the opportunity to try out computers equipped with scanners, braillers, large print fonts and synthesized speech. Rich McGann and Zenola Tyson, two adults who are deafblind, joined us on Saturday evening. One parent said, "I enjoyed meeting Rich and Zenola because it shows that life is possible for the deafblind."

The time and skills of a number of the support staff and education consultants from the ISSP, Ohio, Kentucky, and New York made the weekend a success.

"Members of both the PA Deafblind Project and Overbrook School for the Blind have once again been fantastic —pleasant, patient and kind with all the children (and adults). Sibling sessions were wonderful. The staff at the hotel was great."

UPCOMING EVENTS

FAMILY EVENTS

Two regional Family Learning Retreats are planned for Saturday, January 16, 1999. Information will be sent to families in the near future with further details.

The annual statewide Family Learning Retreat will be held in Grantville, PA on June 25, 26, 27, 1999. The theme will be "Together We're Better: Learning Through Play and Humor." Sessions are being planned for Friday, June 25, for educators, consultants, paraprofessionals, and early interventionists who work with children who are deafblind.

CONFERENCES

The next spring vision conference will be: Wednesday, April 28; Thursday, April 29; and Friday, April 30, 1999. This is a joint planning/collaboration with educators of students with visual impairments (PCEVI), Pennsylvania Association for the Blind (PAB) and Association for the Education and Rehabilitation of Blind and Visually Impaired (AER). The conference theme is "Collaboration: A Vision for the Future."

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Internet Address: www.cisc.k12.pa.us/CISC.pgs/State/DB/DB.html

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e-mail: gardierj@ns.neiu.k12.pa.us

Family Consultant: Stacy Gerlach

Parent Contact: Sue Shaffer
e-mail: shaffers@dickinson.edu

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412-443-1310 (fax)

Education Consultant: Juli Baumgarner
e-mail: baumgar@wisc.org

Family Consultant: Molly Black
e-mail: 74704.156@compuserve.com

Parent Contact: Kristy Smith
e-mail: ksmith@pepper.ncinter.net

This publication is available in alternative media on request. The Pennsylvania Deafblind Project is an equal opportunity employer.

INFORMATION UPDATE (published quarterly)

☐ I enjoyed this issue of Information Update but I am not on your mailing list. Please send future issues to the address below.
☐ I've moved. Please change my address to that listed below.
☐ I receive too many publications. Please remove my name from your mailing list.

Name ______________________ Agency ______________________

Street/P.O. Box ______________________ City ______________________ State ___ Zip ______

Comments ______________________

Call Nancy Lehr at the Project (800-360-7282, ext. 3115) or mail to PA Deafblind Project, Attn: Nancy Lehr, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764.

The Pennsylvania Deafblind Project
serving students with dual sensory impairments

Information Update

Winter 1997

The purpose of this Information Update is to describe project activities and to share ideas. We encourage you to copy and share information, but please provide appropriate citations.

YOU GOTTA DO WHAT YOU GOTTA DO

Searching is an individual, deeply personal journey for answers, for cures, for remediation of your child's disability. There is no right or wrong way to conduct your search. Many people will give you a great deal of conflicting advice. Some will say you're doing too much (maybe you are); some will say you're not doing enough (maybe your aren't) You are the only one who can decide how far, how wide, how long to search You have to try everything you have to try in your search for what your child needs You may do too much, too little, or the right thing at the wrong time, the wrong thing for too long, or the right thing for not long enough. There are no perfect programs, infallible interventions, or quick cures However, you will make some wonderful choices, and your child will benefit from the caring skills of many terrific professionals. You will have your own series of adventures, filled with triumphs and mishaps. Nobody's Perfect.

Excerpted from: Miller, N. B., Burmester, S., Callahan, D. G., Dieterle, J., and Niedermeyer, S. (1994) Nobody's perfect: Living and growing with children who have special needs. Baltimore, MD: Paul H. Brooks Publishing Company, Inc. (p.45).

PENNSYLVANIA CONDUCTS ANNUAL DEAFBLIND CENSUS

Each year, the Pennsylvania Deafblind Project (PDBP) is responsible to report the number of children who are deafblind in Pennsylvania, birth to age 21, to the United States Department of Education. The report is confidential and each child is assigned a unique code number. The information shared with the Department of Education for each child includes: age, sex, severity of hearing and vision losses, other disabilities, cause of deafblindness, and services provided.

Children are usually identified by parents, early interventionists, teachers, therapists, or other related personnel. Identification is based on accurate hearing and vision tests or functional evaluations of hearing and vision. Children who have been diagnosed as having a degenerative condition or disease which is known to affect visual and hearing acuity may also be identified.

PDBP is in the process of collecting and updating the census information. Presently, we have identified over 500 infants, toddlers, preschool, school age and young adults who are dual-sensory impaired. If you have any questions or concerns, please call us.

NATIONAL CONFERENCE ON DEAFBLINDNESS

The National Conference on Deafblindnes is being held June 6-9, 1997, in Washington, D.C. The conference, "The Individua in a Changing Society", will focus on th needs and rights of people who are deafblin and how these needs and rights will b affected by a changing and developing society.

The conference will address a wide array o issues confronting infants, school-ag children, and adults who are deafblind, thei families, and the professionals who serv them. There will be keynote addresses concurrent workshop sessions, posters, an networking time. If you are interested i registration information for the Nationa Conference, you may call the Deafblin Project (800-360-7282) or the Hilton Perkin Program (617-972-7228). The deadline fo registration at the conference, for the lowe cost, is April 6.

The PA Deafblind Project has set asid money via the Family Learning Awards t partially fund parent participation at thi national conference. If you are interested i financial assistance to attend, call the Proje for a Family Learning Award application soon as possible.

'Let us not look back in anger or forward in fear, but around in awareness.'
James Thurber

INTRODUCING ELLEN BLACKBURN

Ellen Blackburn is a Family Consultant for the Deafblind Project. She and her husband, Bob, have one daughter, Taylor, who is six years old and attends Overbrook School for the Blind. Ellen says that her role as Family Consultant has been fun. She goes on to say that it has been a learning as well as a sort-of teaching experience for her. Her goal as Family Consultant is to get more families of special needs children involved in networking. Other than Ellen's role as Family Consultant and taking care of her family, she assists her husband in his financial management consulting business. The business clientele includes corporate and individual planning as well as estate planning for individuals with special needs.

Ellen would love to hear from you. To get in touch with Ellen and her rich New England accent, you may call her at her home (215-884-1474) or call the Project at toll-free 800-360-7282, ext. 3115, and ask Nancy to have Ellen return your call. OR-R-R-R (all those Rs which the New Englanders miss), she can be reached by fax at 215-884-1680 and via e-mail at "dfmltd@erols.com".

FAMILY LEARNING AWARD

The Zielinski family received an award for materials to help them learn American Sign Language which their son uses to communicate. Congratulations!

I HAVE A SISTER, MY SISTER IS DIFFERENT: SO WHAT!

Becky Cornelius, Age 15

Parents and siblings...I mean moms, dads, sisters, and brothers; how's it goin'? My name is Rebecca and I'm 15 years old and I have a sister who is nine years old and really annoying. Her name is Amy and she was born with C.H.A.R.G.E. association. That's an acronym for colabomas, heart problems, atrecia, retarded growth and development, (underdeveloped genitalia in males) and finally ear deformity and/or deafness. My sister has the "C" the "H" the "R" and the "E" which means she is deaf-blind along with some other stuff. But before all the long words and the medical junk, she is my sister and I love her. To me she is just the little blonde haired rug rat who gets into all of my stuff. But other people don't see her that way. The doctors see her as a "case". The teachers and specialists see her as a little girl with problems. To people on the streets, she is "that little girl with glasses". It gets really tiring when, day after day for ten years, you have to explain to someone (or a group of someones) what is wrong with your sister? It is especially hard for me because to me there is nothing wrong with my sister. She is just not like the other kids. In some way, it is better this way because-for-instance-she doesn't talk back when I tell her to do something, she just doesn't do it and when I say something, she doesn't argue or tell me I'm wrong. Most of the time she doesn't respond at all! Pretty cool, huh?

I felt this article would not be complete if I didn't attack the issue of communication. Here goes. My sister communicates through sign, verbal and object communication. Because she is so creative, (she got it from me) she makes up her own signs, which takes my mom awhile to figure out. My mom's kind of slow.

One last thing. To all brothers and sisters out there: the world might think your siblings are "strange," "weird" or "different." But as long as you think they are perfect just the way they are...they are!!!

Reprinted with permission from the California Deaf-Blind Services. Cornelius, Becky. (1996, Summer). reSources, 8, 1.

ON THE INFORMATION HIGHWAY . . . .

The PA Deafblind Project has a web site on the internet. The address of our web site is http:// www.cisc.k12.pa.us. We are on t Instructional Support System of Pennsylvania page. Scroll down t Deafblind Project. Click to open the link for information. You can also send e-mail from here to Mary Frey and eventually also to Juli Baumgarner.

The Project is in the process of further developing this web site t be of assistance to families, educators and service providers. Our Information Update and Information Sheets will be available at the web site. We welcome any helpful ideas to better serve your needs. We are also interested in any web sites you have found to be helpful related to deafblindness. We wou like to link them to our web site for easier access. Give us a call at the office or send an e-mail message.

HAND IN HAND UPDATE

Molly Black, one of our Family Consultants, is setting up a study group for Hand in Hand in the western part of Pennsylvania. The people involved in the project will read an assigned number of pages from the Hand in Hand materials. Via a periodic conference call, they will discuss the information they read and brainstorm ways to use th information to help their child.

If you are interested in a Hand in Hand study group or would like to borrow the materials, please give us a call.

KIDS PAGE

NOTE FROM STACY

Hope everyone had a nice holiday!
I haven't heard from anyone on how it's been going! Hope everything is O.K. Has everybody had snow yet? How much? We live near Philadelphia and we haven't had too much -- as yet!! My daughter, Ashley (11 years old), likes to make snow slushies (snow with fruit punch or ice tea on it). Ricky (9 years old) likes to play football in the snow because "it's messy." Bo (8 years old) likes to go sledding down our street and pulling his friends on their sleds.

Are we ready for our big family weekend? This time, we are going to State College, home of Penn State. Is there anything different from last year's weekend retreat that you would like to do at this year's retreat? What did you like about last year's retreat? And would you like to do it again? What didn't you like about last year's retreat? Help us find some fun things to do. This weekend is for you and we want your input to make it the best for you. Just send a letter with your ideas to me: Stacy Gerlach, c/o Kids Page, 39 Rambler Lane, Levittown, PA 19055.

In the Fall issue of Information Update, we listed a few support groups for siblings and families of multiply handicapped children. Here are several more.

Give Families a Break
United Mental Health
1945 Fifth Avenue
Pittsburgh, PA 15219
(412) 391-1430

Infant Evaluation Program
Attn: Kathryn Groves
950 East College Avenue
State College, PA 16801
(814) 231-0138

Siblings That Are Really Special (STARS)
c/o American Cancer Society
1626 Locust Street
Philadelphia, PA 19103
(215) 985-5311

Kate Mueller, MSW
Easter Seals
599 Lincoln Highway
North Versailles, PA 15137

Look how big Molly Black's children have grown. Alex (5), Abbey (19 months), and Bethany (9)

Come on, kids!! We would love to hear from you. Send in your cards, letters, photos, drawings, short stories, parents (opps! no-no), just anything that you would like to share with other kids and families out there. Send your submissions to: Kids Page, c/o Stacy Gerlach, 39 Rambler Lane, Levittown, PA 19055.

Billy Gerlach (6) loves his new drum set. He hits the button with enthusiam and plays different songs.

RESOURCES AVAILABLE FROM THE PROJECT

Pennsylvania was one of several states to sponsor the development of three assessment guideline booklets for use with children who dual sensory or multiply impaired. The contents of the documents were field tested and reviewed before publication. Call Nancy at the Project to request any of them.

Siegel-Causey, Ellin, Ph.D. (1996). Assessing young children with dual sensory and multiple impairments (Ages birth to five years). Columbus, Ohio: GLARCDB.

Downing, June, Ph.D. (1996). Assessing the school-age student with dual sensory and multiple impairments (Ages 6-15). Columbus, Ohio: GLARCDB.

Everson, Jane, Ph.D. (1996). Assessing the transition needs of young adults with dual sensory and multiple impairments. Columbus, Ohio: GLARCDB.

➡ ➡ ➡ UPCOMING EVENTS FOR THE PA DEAFBLIND PROJECT ⬅ ⬅ ⬅

Instructional Support System of Pennsylvania Statewide Conference	Grantville	March 18, 19, 1997
National Technical Assistance Consortium (NTAC) for Children and Young Adults Who Are Deafblind	Philadelphia	March 19-21, 1997
1997 Deafblind Project Family Learning Retreat	State College	April 11-13, 1997
Transition Team Partnerships Workshop	CISC, Harrisburg	May 29, 1997
National Conference on Deaf-Blindness	Washington, D.C.	June 6-9, 1997
Advisory Council Meeting	Statewide	June 4, 1997

Write or call us with your ideas and questions, or if you would like some technical assistance from the Deafblind Project.

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412-863-1283

Stacy Gerlach
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Levittown, PA 19055
215-945-7364

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INFORMATION UPDATE (published quarterly)

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Street/P.O. Box ______________________ City ______________ State ___ Zip ________

Comments ____

Call Nancy Lehr at the Project (800-360-7282) or mail to PA Deafblind Project, Attn: Nancy Lehr, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764

The Pennsylvania Deafblind Project
serving students with dual sensory impairments

Information Update

Issue No. 6

Fall 1997

The purpose of this Information Update is to describe project activities and to share ideas. We encourage you to copy and share information, but please provide appropriate citations.

The 1997 National Conference on Deafblindness

The Pennsylvania Deafblind Project sponsored six parents and co-sponsored one parent through Family Learning Awards for attendance at the National Conference held this past June in Washington , D.C. The National Technical Assistance Consortium sponsored the attendance of two more parents from Pennsylvania. We had quite an impressive representation of parents from PA! Mary and Juli, the Project's education consultants also attended. Parents were asked to share their impressions, reactions, and information from the conference. If you would like to further discuss what we learned at the conference, or wish to speak directly to the parents who attended, please contact Nancy Lehr, Project Assistant.

LINDA HILDEBRAND

"The National Conference was fantastic, so uplifting. I am trying to hold it in my mind to see the beauty of it. All the sign language, all the interpreters. They did a wonderful job of putting it all together—so accommodating. It was neat to see all the FM systems working, and everyone pausing and looking for cues; that was the way they did their presentations. Communication was a huge message throughout the conference. Communication is a topic that keeps coming up in our household.

I attended a banquet and listened to a story teller who is deafblind. To watch the story teller and to look around the room and see people one-on-one, using different ways of communicating, each beautiful in its own way, and laughing..."

STACY GERLACH

"I loved learning "firsthand" at the conference, and wished that more fathers could have attended. My husband, Rick, was home, manning the fort in my absence. One of my favorite sessions included a discussion about some of the feelings and reactions of fathers. The presenter mailed information to me later about starting up groups for fathers.

• • • • • • • • • • • • • •

". . . to look around the room and see people one-on-one, using different ways of communicating, each beautiful in its own way, and laughing . . ."

• • • • • • • • • • • • • •

In a session that featured first-hand perspectives from adults who are deafblind, I listened to the expression of frustration regarding the need for everyone to understand that all behaviors mean something, that they communicate something for us to listen to.

Another session focused on adapted physical education. The session provided examples of adaptations, such as a light behind a basketball hoop, and a loud buzzer that signals when a basket is made. This year, I will pursue having my son Billy participate with the other children at his school in gym class. I have a handout with suggestions for the gym teacher.

At the end of the conference, the National Technical Assistance Consortium (NTAC) hosted an action planning session for parents. Parents worked in small groups to discuss the

(continued on page 2)

CHECK OUT THE ENCLOSURES WITH THIS ISSUE!!

- **Information Sheet: Surfing the Web**
- **A letter from Janna**

The 1997 National Conference on Deafblindness

(continued from page 1)

conference and to plan any follow-up at home. I felt that the action planning session was very good, since it gave me another chance to learn from other parents."

ANDREA AND LEN JOHNSON

"This is the second time that we have had the opportunity to attend the national conference. We enjoyed this year more because there was better family representation. It was a great place to get ideas from other states. A big highlight of the conference was to see presenters who, themselves, were deafblind, and other deafblind participants in which we could see our child actually becoming."

ELLEN BLACKBURN

"I am just so glad I had the opportunity to attend the national conference...so positive and uplifting. And, there were way too many interesting concurrent sessions from which to choose. It was difficult to decide which to attend."

MOLLY BLACK

"It confirmed for me that finding a way to communicate for Alex is our number one priority. If our kids can't communicate, then they're not going to participate. To see it in action...that individuals with deafblindness can contribute to society as long as someone is available to them to intervene in their type of communication.

One of the sessions that made an impression was the "You & Me: Communication" session in which a videotape was shown and discussed. The mother of the boy on the videotape was at the session. It impressed me that the video showed a child so involved, yet they were able to place him in a regular classroom. "You & Me" is a series of four videotapes about one child. The videotape in this session featured the mother very much on top of things; she just knew what the goals were for her child. It impressed me that the assistant wasn't particularly trained, other than knowing sign language."

JEAN WEAVER

"I was overwhelmed at the amount of variations of sign language. The fingerspelling/sign language really floored me, knowing that this very well might be the way that we are going to have to communicate. It gave me the push to get on the Internet. It was awesome."

RALPH WARNER

Ralph, currently president of the National Family Association for the Deafblind (NFADB), as well as president of PA Parents for the Deafblind, was a featured speaker at the conference. He spoke candidly about the dramatic but positive changes that occurred in his family after the birth of his son, Adam. He shared some of the frustrations and reactions of families, including his own, as they work with the "system," and provided suggestions on how to help people who are deafblind achieve their fullest potential.

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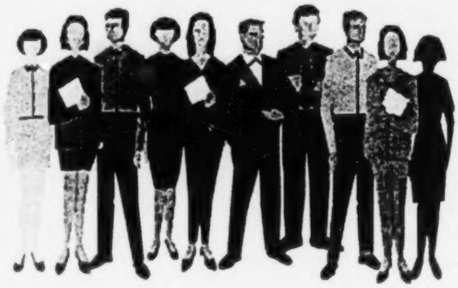

FEDERAL CENSUS CHANGES

This year, the annual federal census forms sent out by the Pennsylvania Deafblind Project, on behalf of the Bureau of Special Education, will have a new look. Information will be requested regarding dates and results of medical and functional assessments of vision and hearing. The form will have more check boxes and less writing regarding the identified or suspected cause of deafblindness. Other requested information will reflect the changes brought about by IDEA 1997. The revised census forms with instructions will be sent out in early 1998 to school districts, intermediate units, and early intervention service providers. Watch the mail for the census forms and please return the completed forms by the identified due date. If a previously identified child has moved or left your district or agency since June 1997, please forward that information to the Project by phone or mail. Contact Mary or Juli, education consultants, if you have any questions.

FAMILY LEARNING RETREAT: YOU AND ME

On September 27, 1997, two workshops were conducted simultaneously in both eastern and western Pennsylvania. The theme "You & Me" focused on coordinated efforts among the family, school, and community in order to develop a successful educational program for the student who is deafblind. "You & Me" is a series of four videotapes with two booklets which can be used for training. (See "Pertinent Resources" on this page for details.)

Seven families attended the two sites. Each family was allowed to invite guests. Present as guests were Sunday school teachers, a classroom instructional assistant, a nurse, a hearing therapist, and a classroom teacher.

Communication programming, inclusion, the use of paraprofessionals to support students who are deafblind, socialization, and other topics were discussed. Parents and guests enjoyed having the opportunity to meet and discuss the topics while inclusive activities were provided for the children.

Discussion of the use of paraprofessionals to support a student who is deafblind included these points:

The role of the paraprofessional must be described through the student's written plan (IFSP or IEP). The educational team, including the family, design the student's objectives, goals, and instructional strategies. The paraprofessional is there to help the student achieve the objectives and goals as described on the student's written plan.

It is critical that the paraprofessional utilize the student's preferred mode of communication with the student. For example, if the student uses tangible object symbols, the paraprofessional should use tangible object symbols. If the student uses sign language, the paraprofessional should also use sign language.

For a student who is deafblind, a paraprofessional may share in the role of bringing the world to the student. For example, if the student is unable to receive information through their distance senses of vision and hearing without assistance, the paraprofessional may need to describe pertinent information about the environment, what is happening, who is present, to the student.

The following is just one of the many ways that the information shared at Regional Learning Days about paraprofessionals can be applied. The Project's education consultants may provide technical assistance to teams to determine what may be helpful, appropriate or adapted for individual students in their respective programs.

At a recent IEP meeting for a high school student who is deafblind, and who is enrolled in a chemistry course, discussion occurred about how the student could conduct experiments that might be considered dangerous. The student's aide listened to a description of a typical experiment, looked at the group, and said, " I will be her eyes and hands." The consultant was able to help the team set up an action plan to assist the aide in carrying out this strategy.

A follow-up regional day on "You & Me" is scheduled in Western PA for January 24, 1998. (See page 6 for details.) Please share any other ideas for topics or activities for future Regional Learning Retreat days with Project staff.

contributed by
Juli Baumgarner and Mary Frey

PERTINENT RESOURCES

You & Me. (1995). Monmouth, OR: Teaching Research Division. Riley Ford who is totally blind and has a profound hearing loss, is portrayed as he attends his neighborhood school.

You & Me: The interpreter-tutor. (1995). Monmouth, OR: Teaching Research Division. The role of the interpreter-tutor for a student who is deafblind is described, with applications for many other students, in the video and booklet.

You & Me: Communication. (1995). Monmouth, OR: Teaching Research Division. The methods of communication used by Riley, why those methods were chosen, and how others in the school environment use them to communicate with Riley are shared in the video and booklet.

You & Me: Social connections. (1995). Monmouth, OR: Teaching Research Division. The importance of movement and mobility in building social connections for a child who is deafblind are shown.

(November 19, 1996). What are all the adults doing in my classroom? This video of a teleconference describes effective strategies to train and coordinate with paraeducators and others in the classroom, with examples shown of specific students. Available from the Distance Learning Center in Gibsonia, PA; 800-446-5607 (in PA only) or 412-443-7821.

THE PROJECT ON THE WEB

The Pennsylvania Deafblind Project has a page on the worldwide web. We are listed as part of the Pennsylvania Instructional Support System. The web address is http://www.cisc.k12.pa.us.

1. Once you have entered this web address and opened the site on your computer, you will see the name "Central Instructional Support Center (CISC)."

2. Three buttons appear under CISC. Choose the button that says "State Services."

Regional Services	State Services	Autism

3. When you hit that button, you will see boxes with a number of projects listed under "Statewide Services."

Assistive Tech. State	Autism Statewide	Deafblind Project	etc.

4. Choose the button that says "Deafblind Project." There are a number of choices on the Deafblind Project page which give you further information. Enjoy exploring our page which is updated periodically.

The CISC web page also has a number of listserv discussion groups just beginning, including one on sensory impairments.

A. After getting on the CISC web page (step 1 above), instead of hitting the button for "State Services," scroll down to "List Serv Discussion Groups."

B. In the List Serv Discussion Groups, there is a group for the sensory impaired called "SENSORY_IMPAIRED_CISC."

C. In order to subscribe (at no cost) to the sensory impaired listserv, follow the directions on the web page. Eventually, there will be questions and discussions going back and forth among all the participants in this group. The listserv is fairly new, so we invite you to begin a discussion.

There are other resources available to you on the CISC web page or linked to it. Feel free to explore them.

Many resources related to deafblindness are also available on the world wide web. The following list is a sample of several that have proven useful to the Project consultants. If you find any useful websites, please call the Project office or email us to share that information. Thank you.

DB LINK - a national clearinghouse for deafblindness	http://dblink@tr.wosc.osshe.edu
National Organization for Rare Diseases, Inc. (NORD)	http://www.pcnet.com/~orphan/
National Family Association for Deaf-Blind	http://www.helenkeller.org/national/special.htm
Service Providers for Deafblind People in the USA	http://www.eng.dmu.ac.uk/~hgs/deafblind/dbplaces_usa.html

article contributed by Mary Frey

*** See the related article on the Information Sheet: "Surfin' the WWW with Jean." It is a first person story of how one Pennsylvania parent of a deafblind child has been surfing the net for information and interaction.***

RESOURCES AVAILABLE ON LOAN

📖 Alsop, L. (Ed.). (1993). A resource manual for understanding and interacting with infants, toddlers, and preschool age children with deaf-blindness. H.O.P.E., Inc., Logan, Utah. This manual provides information and intervention strategies for people who work with young children who are deafblind. Various areas of development are discussed, and sample activities are described in detail. Also included is information on children with deafblindness and special health care needs. This is a resource for teachers who may be working for the first time with a young child who is deafblind, for seasoned teachers who might enjoy expanding on their resources, and for parents.

📖 📼 Chen, D., & Schachter, P.H. (1997). Making the most of early communication: Strategies for supporting communication with infants, toddlers, and preschoolers whose multiple disabilities include vision and hearing loss. NY, NY: AFB Press. The video with companion guide booklet can be used for training or self-study by families or service providers who work with young children who are deafblind. Very young children with deafblindness are shown in a variety of settings, with components illustrating the impact of vision and hearing loss on communicative interaction.

📖 Miner, I., & Cioffi, J. (1997). Usher Syndrome in the school setting. Sands Point, NY: Helen Keller National Center. This manual provides information about Usher Syndrome and the importance of early instruction and planning, in conjunction with appropriate mental health support. Primarily written in a question-and-answer format, it is a useful tool for families, teachers, and other service providers of students with Usher Syndrome.

PARENT GROUPS THAT MAY INTEREST YOU

PENNSYLVANIA PARENTS FOR DEAFBLIND

Pennsylvania Parents for Deafblind is comprised of parents, families, and other people concerned about the welfare of individuals who are deafblind. For more information, contact Mr. Ralph Warner at 215-679-5432.

Pennsylvania Parents of Deaf or Hard of Hearing Children

We are parents of children with hearing losses and are from various counties across the state. Our mission statement best describes our purpose.

The mission of the **Pennsylvania Parents of Deaf or Hard of Hearing Children** is to enhance parents' knowledge, understanding and confidence in providing total quality participation in education, family, and the Deaf and hearing communities.

If you are interested in receiving information about a new, statewide organization being formed for parents of children who are Deaf or hard of hearing, please return this form in an envelope to: Pennsylvania Parents of Deaf or Hard of Hearing Children, c/o Pam Johnson, 112 Springhouse Road, Lancaster PA 17603

Name: ____________________

Street Address: ____________________

City, State and Zip Code: ____________________

County: ____________________

Telephone Number (optional): ____________________

UPCOMING EVENTS

TELECONFERENCES

Visual Impairment and Social Skills: Effective Techniques and Interventions discusses the critical social skills needed for success, with information about social skills instruction. Register at a downlink site near you by calling the Distance Learning Center at 800-446-5607 (PA only) or 412-443-7821, ext. 292, or Deb Holzapfel, ext. 222, for program information. — December 18, 1997

Visual Impairment and Autism: What Does it Look Like? What can we do? includes information and strategies for students with visual impairments and autism. Register at a downlik site near you by calling the Distance Learning Center at 800-446-5607 (PA only) or 412-443-7821, ext. 292, or Deb Holzapfe, ext. 222, for program information — January 24, 1998

FAMILY ACTIVITIES

Western Regional Learning Day for Families, Irwin, PA (east of Pittsburgh). Call Molly Black, PA Deafblind Project Family Consultant, at 412-863-1283, or Nancy Lehr at 800-360-7282 (PA only) or 717-541-4960. — January 24, 1998

PA Deafblind Project Family Learning Retreat, Holiday Inn-Hershey/Harrisburg, Grantville, PA. Call Nancy Lehr at the PA Deafblind Project for more information. — June 26-28, 1998

CONFERENCES

Spring Conference for Service Providers in the Field of Visual Impairment at Holiday Inn-Hershey/Harrisburg, Grantville, PA. This conference, with a theme of "Transitions", focuses on practical tips for all service providers of individuals with visual impairment. A special pre-conference institute will be held on April 29. For a registration packet, please call Anna Craig, IU 4, 412-652-3302 — April 29, 30, May 1, 1998

Write or call us with your ideas and questions, or if you would like some technical assistance from the Deafblind Project.

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Ellen Blackburn
533 Waln Road
Glenside, PA 19038
leave message at 800-360-7282 (PA only)

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Street/P.O. Box ______________________ City ______________________ State ___ Zip ________

Comments ______________________

Call Nancy Lehr at the Project at 800-360-7282 (in PA only) or 717-541-4960, ext. 3115, or mail to PA Deafblind Project, Attn: Nancy Lehr, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764.

The Pennsylvania Deafblind Project

serving students with dual sensory impairments

Information Update

Spring 1997

The purpose of this Information Update is to describe project activities and to share ideas. We encourage you to copy and share information, but please provide appropriate citations.

MAKING CONNECTIONS – AT THE FAMILY LEARNING RETREAT

The annual statewide Family Learning Retreat was held on April 11, 12, 13, 1997, at the Nittany Lion Inn in State college. The theme was "Making Connections: Hand in Hand". Twenty families enjoyed the weekend with staff and childcare workers. Families had the opportunity to make connections with other families and staff members, sharing and discussing their concerns with others who understand.

WEEKEND ACTIVITIES

In the sibling sessions, brothers and sisters enjoyed the chance to share what they felt and thought about having a sibling with disabilities. The children with disabilities had an opportunity to interact and do a lot of activities.

Parents learned how to get their family more involved in their communities, focusing on a desired activity to work through the process. A framework was provided for mapping the resources available in the family's local community. Small groups of parents worked through the steps together, learning from each other. Thoughtful consideration was given as each family mapped out their own interests such as recreation, sports, arts, theater, church. Each family focused on one community activity which they would like to pursue and what support may be needed to achieve that goal. Time was given to discuss ways to use that community's resources to meet the family's wish to get more involved. Group discussion ensued about how to tie together the skills needed for the chosen activity, with the goals and objectives developed for an IEP and an IFSP for the child. First steps were laid out in an action plan to begin upon returning home.

The families identified the need to consider the following items: the setting of the activity (swimming pool, athletic field, church, grocery store, circus, etc.); the information needed to gather about the activity (schedule, fee, details); and the kind of support systems that were available (family, friends, neighbors, volunteers).

They brainstormed about what questions to ask when making phone calls for further information. They talked about the need to respect the family's priority -- were they a family who liked to camp, or preferred to go to the library, or were very involved in their church. Everyone concluded that the whole process took some preplanning. There are inclusion challenges everywhere. There definitely is a need for increased communication with community agencies. Hopefully, all this work results in increased interaction within the community and more of a feeling of belonging for that child and his or her family. (See stories about Alex, Billy, and Taylor for successful experiences.)

The Family Retreat was a mutual learning experience for all -- a real demonstration of collaboration in action!

PARENTS SHARE EXPERIENCES AND HINTS

Alex

Molly, the first parent who spoke at the retreat, was one of the inspirations for this Deafblind Project Family Learning Retreat. Her story regarding Alex's participation in Vacation Bible School (VBS) was featured in a previous edition of Information Update. Molly, mother of Alex, Abbey and Bethany talked about involving Alex, her son with dual sensory impairments, in VBS. Molly wanted Alex to attend VBS. The church worked out an arrangement in which they provided a babysitter for Abbey, Alex's 2-year-old sister, while Molly came to VBS to help with Alex. At first, the other children were puzzled and asked "Why doesn't Alex talk?" and other questions; but quickly, the children included Alex in their activities. Molly reported that Alex got more turns on the slide than anyone else, and the children competed over who got to be Alex's friend!

Molly's hints: "The church community knew us. If they know you, they will know your needs. Have a plan. Don't just drop off your child."

Molly reported that this year, the church has already reached out and contacted her. She will be working with the church to set up ways for Alex to participate without

(con't next page)

MAKING CONNECTIONS (con't from previous page)

Molly's full-time assistance. Molly is also exploring ways for Alex to be included in his neighborhood school.

Billy

Stacy began by showing her son Billy's baseball picture. "I have four kids. They're not with me today. The reason is that everyone's at baseball. Billy is in the regular Little League. It was hard . . . Pictures are tomorrow and he's gotta be there! Today's opening day!"

Stacy, mother of four children, shared her story about enrolling Billy, who is deafblind, in the community T-ball little league. Stacy asked to include Billy when she was enrolling his brothers in baseball league. When she approached the local president of the league, he wasn't sure about what to do.

Stacy called the state organization that oversees Little League baseball, and it recommended that Billy be included with the other children in his neighborhood T-ball league. The other children take turns wheeling Billy around the bases, and she jokes that she likes when the children loudly discuss whose turn it is so Billy can hear them! Stacy said that it was helpful that everyone already knew Billy, from his attendance at his brothers' games, and also that she was persistent in finding support for his enrollment.

Stacy also talked about her family's experience at their community public library. On a family outing to the library, Stacy discovered that the building was inaccessible to a wheelchair user. There were steps leading up into the library and steps down into the children's section. She contacted her state legislator to ask why Billy did not have the chance to enjoy the public library. The library was receptive to learning about ways to make the library accessible, and funding was obtained. Billy was the first person to open the door to the newly-accessible library. He now enjoys the library with his three siblings. Her strategies included enlisting local support and collaboratively designing solutions.

Stacy's hint: "Just ask 'why?' "

Taylor

Ellen, Taylor's mom, says that attempts to include Taylor in the community Little League are "a work in progress". A community member approached Taylor's mom, Ellen, about getting a "Little Challenger" Little League (LCLL) started. It has been a challenge, but with progress. Initially, when asked, the athletic director said it was not possible to begin a LCLL because of liabilities. The Philadelphia Phillies were approached and they decided to sponsor the league. A social event was held at the ballpark, with the Philly Phanatic (Philadelphia Eagles team mastcot) and Bill Bergey (Eagles quarterback), and pizza donated by a local pizza parlor. When the other children in the separate fields saw what a wonderful time these children were having, they came over to join them. This year, there will be a Challenger Field Day, and a Challenger Little League. A girls' team is buddying up with the Challenger Little League. The teams are starting to rotate in the schedule. On April 10, at the first home game of the Phillies, one of the Challenger Little League kids was invited to throw out the opening pitch!

Ellen reported that it took four years for the Challenger Little League to happen. This began as a separate activity, but has resulted in many connections

Ellen suggested that if you are interested in involving your family in a community activity:

1) Identify a setting that is of interest. It may be a new setting, or one in which you would like your entire family to be involved.

2) Make the necessary arrangements to arrive -- in other words, transportation. If the whole family is participating, you will already know how you're getting there. If not (e.g., vacation bible school), consider car pooling, community resources.

3) Decide what is needed for the child to participate in that activity

4) Determine whether everyone had enough fun to warrant returning to the activity. ▸▸▸▸

Remember: Fun is the goal! ☼

RESOURCE BOOKS AVAILABLE

☛ Schleien, Stewart J., Ray, M. Tipton, and Green, Frederick P. (1997). Community recreation and people with disabilities: Strategies for inclusion. Baltimore, MD: Paul H. Brooks Publishing Company.

This book is aimed at professionals dealing with special education, therapeutic recreation, community recreation, and for anyone who wants to be an effective leisure advocate for persons with disabilities. It contains a number of strategies and creative ideas for inclusion. It helps one look at how community recreation programs can encourage the participation of everyone in the community regardless of levels of ability. It has a number of screening devices, evaluation tools, and forms to help one assess a community's opportunities for leisure recreation for persons with disabilities.

☛ Diamant, Rachal B. (1992). Positioning for play: Home activities for parents of young children. Tucson: AZ Therapy Skill Builders.

This is a book with a number of activities to assist parents of children, birth to three, who have developmental delays. It has a number of movement and play experiences. It has easy-to-follow illustrations and gives ideas of ways to hold and play with children while providing opportunities to develop motor skills and stimulation. Set up with activities to be used with household items, it provides parents with the correct positioning for their child.

☛ Everson, Jane M. (ed). (1995). Supporting young adults who are deafblind in their communities: A transition planning guide for service providers, families, and friends. Baltimore, MD: Paul H. Brooks Publishing Company.

This is a book about transitions and the services that are needed to bridge the gaps in the lives of people who are deafblind so that they can achieve a higher quality of life and be assured of their human dignity. It contains information, strategies, forms, case studies or stories about high school students and young adults who are deafblind, inventories regarding possible future plans, maps, etc.

KIDS PAGE

SIBLINGS SHARE THEIR THOUGHTS AT RETREAT

At the April, 1997 Family Learning Retreat, sponsored by the Pennsylvania Deafblind Project, sibling groups were facilitated by Jane Stewart and Linda Critchlow, early intervention service providers. Jane and Linda worked with children of many ages using art, stories, a video, and discussion of issues related to having a brother or sister who is deafblind. They reported that the siblings were delightful! Here are highlights of what they shared with the parents at this retreat: Siblings of all ages (from three to sixteen) talked about being afraid when a family member goes to the hospital, because they fear the person will not return. The child needs to be reassured, and his or her questions answered at the appropriate age level. Jane and Linda said, "Talk to them... This might be hard...Their biggest concern is not fear of the hospital, but a fear that a family member might die."

One comment that the facilitators expected to hear more often was that siblings get tired of having to help out. Yes, they do get tired of having to do things for the brother or sister, but their empathy was extremely evident. They expressed empathy towards not only their brother or sister, but to others. It hurts siblings when they hear derogatory comments about others.

Open communication about the cause (known or unknown) of the disability is important, because the siblings expressed fear of having or "catching" the disability.

Open communication about routines and rules is also critical. A few siblings made comments such as "We don't know how we are supposed to act because they (parents) don't tell us."

Jane and Linda recommend: "Always make sure you keep the siblings aware of what is going on. Answer their questions at their level, but always be honest."

* * *

GRANDPARENTS

The February/March 1997 issue of "Pennsylvania Early Intervention: A Publication of the Pennsylvania Interagency Coordinating Council" featured grandparents supporting and sometimes raising their grandchild with a disability. One of the resources listed in the newsletter was the AARP Grandparent Information Center, 601 E. Street, NW, Washington, D.C. 20049; phone (202) 434-2296. It is a source of information and a referral agency for local and national resources that include grandparent support groups, and also provides technical assistance to groups that address the needs of grandparent caregivers. Parent-to-Parent of Pennsylvania (800-986-4550) may also be contacted if you would like to know more about support for grandparents.

SPECIAL NEEDS KIDS

Why do people make fun of handicapped kids? Is it the way they do things, the way they move, or is it just because they are different from us? I have a sister who is deaf and blind. I have seen kids who lay on the floor and drool. Also, I have seen kids who professionals say would never move and are almost walking. What enables kids to do this is a lot of love. My sister is walking and almost talking. She is always saying bigger and more difficult words. She is loved by a lot of people. We started walking with my sister when she was two. Today, she is running. It's because of all the love she has around her. There are all sorts of handicaps, including cerebral palsy and downs syndrome. When I went to Penn State to attend a camp from April 11-13, I saw many loved kids who are wheelchair bound. There were some kids on oxygen and vocal assisted communication aids. I see these children as very unique individuals.

The above article was written by ***Joe Weaver****, age 13. Joe is in 8th grade and on the staff of the school's newsletter, "Prexie Press", at Washington (PA) Middle School.*

In the last few issues of "Information Update", we have listed several support groups for siblings and families of children who have multiple handicaps. Here are three more:

Sibs Only
% Easter Seal Society
Attn: Joan Charlson
632 Fort Duquensne Blvd.
Pittsburgh, PA 15222
412-281-7244

Overbrook School for the Blind
Attn: Anne Felton
6333 Malvern Avenue
Philadelphia, PA 19151-2597
215-877-0313

The ARC of Dauphin County
Attn: John Sebastian
4309 Linglestown Road
Suite 114E
Harrisburg, PA 17112
717-540-5800

UPCOMING EVENTS FOR THE PA DEAFBLIND PROJECT

State Transition Team Partnerships Meeting	CISC, Harrisburg	August 28, 1997
INSITE Training (Days 1 and 2)	IU 16, Lewisburg	Sept. 9-10, 1997
Regional Learning Retreat Day East	Morgantown	Sept. 27, 1997
Advisory Council Annual Meeting	CISC	Sept. 23, 1997
Local Transition Team Partnerships Workshop	WISC, EISC	Sept. 24-25, 1997
Regional Learning Retreat Day West	Hermitage	Sept. 27, 1997
PA CEC Conference	Grantville	Nov. 6-7, 1997
INSITE Training (Days 3 and 4)	IU 16, Lewisburg	Dec. 2-3, 1997
TASH Conference	Boston, MA	Dec. 10-13, 1997
Family Learning Retreat - Statewide	Grantville	June 26-28, 1998

TRANSITION TEAM WORKSHOP

A workshop is scheduled on September 24 and 25, 1997, in eastern and western Pennsyvlania for community teams that would like to enhance the transition to adult life for a young person who is deafblind. As part of an ongoing effort supported by the Pennsylvania Deafblind Project and the State Transition Team for Individuals who are Deafblind, the workshop will address successful interagency team strategies, as well as issues related to promoting the independence of the young person who is deafblind. Please call the Project for more information or if you are interested in participating.

Write or call us with your ideas and questions, or if you would like some technical assistance from the Deafblind Project.

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(717) 541-4960
e-mail: mfrey@cisc.k12.pa.us

Juli Baumgarner
PA Deafblind Project
5347 William Flynn Highway
Gibsonia, PA 15044
(800) 446-5607, ext. 238
(412) 443-7821, ext. 238

Family Consultants:

Molly Black
610 Rembrandt Circle
Irwin, PA 15642
(412) 863-1283

Ellen Blackburn
533 Waln Road
Glenside, PA 19038
(215) 884-1474
e-mail: dfmltd@ erols.com

Stacy Gerlach
39 Rambler Lane
Levittown, PA 19055
(215) 945-7364

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INFORMATION UPDATE (published quarterly)

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Call Nancy Lehr at the Project (800-360-7282) or mail to PA Deafblind Project, Attn: Nancy Lehr, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764

The Pennsylvania Deafblind Project
serving students with dual sensory impairments

Information Update

Fall 1996

The purpose of this Information Update is to describe project activities and to share ideas. We encourage you to copy and share information, but please provide appropriate citations.

NEWLY-FORMED ADVISORY COUNCIL

On September 24, 1996, the Advisory Council for Children who are Deafblind held their first annual meeting in Harrisburg. It was an industrious and productive day of developing the mission statement, outcomes, and action planning for the Deafblind Project. Dr. William Penn, Director of the Bureau of Special Education, PA Department of Education, attended a portion of the meeting.

In addition to Juli Baumgarner and Mary Frey, Education Consultants for the Deafblind Project, members of the Council include: Mary Anketell, Education Consultant with Early Intervention Technical Assistance; Molly Black, Ellen Blackburn, and Stacy Gerlach, parents and Family Consultants with the PA Deafblind Project; C.J. Carroll, Jill Fitch and Andrea Johnson, parents and representatives of PA Parents for the Deafblind; Kathryn Daugherty, Special Education Support Specialist at the Conroy School in the Pittsburgh School District; Kathleen Huebner, Program Director at Pennsylvania College of Optometry; Bernadette Kappen, Director of Overbrook School for Blind Children; Rich McGann, consumer from Pittsburgh; and Fran Warkomski, Project Director of Central Instructional Support Center.

The next annual meeting is scheduled for September 23, 1997. During the interim, information will be shared and issues discussed via periodic conference calls.

For more information, contact the Project.

PENNSYLVANIA HAPPENINGS

"Deafblind" . . . In Pennsylvania, we have begun to use the single word "deafblind" rather than "deaf-blind" or "deaf/blind" to encourage recognition that both vision and hearing impairments are involved for an individual.

Accurate identification . . .The Deafblind Project is preparing to send out the Annual Deafblind Federal Census in January. Each early intervention service agency, preschool program, school district, intermediate unit and charter schools for the deaf and for the blind are sent census packets. The purposes of the census are to: 1) update the information of children previously identified; 2) identify new children; 3) examine the gathered data for demographic trends impacting upon future activities; 4) offer technical assistance and training to families, educators, and service providers.

Keeping in touch . . .On the first Tuesday of each month, staff at the Deafblind Project and representatives from the PA Parents for Deaf-Blind Group share information, talk about upcoming events, reflect on recent activities, and brainstorm issues via an evening conference call. For further information, contact Ralph Warner (215-679-5432) or Andrea Johnson (610-623-8541) or staff at the Deafblind Project. ☎

Regional Days . . .Twenty-nine parents and educators met in Philadelphia to participate in the workshop, "Strategies for Learners who are Deafblind" on September 7, 1996. There was a wonderful exchange of information and ideas culminating in specific child-oriented action plans. Some participants took advantage of the chance to borrow the resource materials, "Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind" on which the workshop was based.

Hermitage was the location for the Western Regional Day workshop on October 19, 1996. Five families, two educational interpreters, one Sunday School teacher/librarian, and a nurse attended the workshop. Sibling groups were also conducted with feedback to the families.

National Conference on Deafblindness: The Individual in a Changing Society will take place June 6 through June 9, 1997, in Washington, D.C. The PA Deafblind Project is offering special Learning Awards to assist with expenses for several families to attend the national conference. Contact the Project to request a Conference Learning Award application form.

Reminder: Learning Awards are available to families to help improve the effectiveness of education and experiences for their child who is deafblind. One parent is using a Learning Award to defray costs of attending the TASH Conference. One family is considering attending a sign language course. Another family plans on buying a set of "Hand in Hand" books. Be creative! If you need an application form, call the Project. The next two deadlines are December 31, 1996, and March 3, 1997.

RESOURCES AVAILABLE ON LOAN FROM THE DEAFBLIND PROJECT

The following materials contain information about Individualized Education Plans (IEPs) and Individualized Family Service Plans (IFSPs)

Downing, June E., Ph. D. (1996). Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers. Baltimore, MD: Paul H. Brooks Publishing Company.
This practical book offers concrete suggestions and strategies to meet the unique challenges of learners who have one or more sensory impairments. It includes case studies from preschool, elementary school, and secondary classrooms. (196 pages)

Haring, N.G. & Romer, L.T. (1995). Welcoming students who are deaf-blind into typical classrooms: Facilitating school participation, learning, and friendships. Baltimore, MD: Paul H. Brooks Publishing Company.
This book provides a comprehensive picture of inclusionary practices across the United States. It reflects the experiences of educators and parents regarding the complex instructional support needs of students who are deaf-blind. (447 pages)

Huebner, K., Prickett, J.G., & Welch, T.R., Joffee, E. (eds.). (1995) Hand in hand: Essentials of communication and orientation and mobility for your students who are deaf-blind. New York, NY: AFB Press.
This set of materials is designed in modules. Each section offers state-of-the-art information, hints, guidelines, strategies, articles, and a variety of other resources specific to deafblindness. (2 books, 1 trainer's manual, 1 book of article reprints, 1 videotape)

McGahee-Kovac, Marcy. (1995). A student's guide to the IEP. Washington, D.C.: NICHCY.
This free guide offers students practical steps and examples of contributing to the development of their own IEP from preplanning to the actual meeting. This booklet also has a cassette tape available on loan. (12 pages)

NICHCY. (1995). Helping students develop their IEPs: Technical assistance guide. Washington, D.C.: NICHCY. (Volume 2, December).
This free easy-to-read guide is designed for parents and educators. It guides them in how to assist students to take an active role in developing their own IEP. (24 pages)

Mancuso, E., Rieser, L., & Stotland, J.F. (1991). The right to special education in Pennsylvania: A guide for parents. Philadelphia, PA: The Education Law Center.
This free booklet offers a section on the IEP conference, the IEP team, tips on developing IEPs, how to settle IEP disagreements, and IEP timelines. (56 pages)

* * * See separate Information Sheet on "Considerations in IEP Development for Children Who Are Deafblind" * * *

INTRODUCING MOLLY BLACK

Molly, one of three parent consultants for the PA Deafblind Project, lives in Westmoreland County with Abigail (18 months), Alex (five years), Bethany (nine years), and husband Garth. In addition to her part time position as a family consultant, she is completing a term as co-chair of her Local Interagency Coordinating Council, and is a trainer for EPIC. EPIC (Educating Physicians in the Community) is directed toward helping physicians learn about early intervention, referral strategies, and available services.

Molly's son, Alex, has both a visual and hearing impairment due to Cornelia de Lang Syndrome (CDLS). Molly volunteers as the Western PA Regional Coordinator for CDLS, supporting families with information about community resources, advocacy, and emotional support.

On top of all this, Molly is assistant troop leader for daughter Bethany's Girl Scout troop! Molly credits her husband, Garth, for his support "behind the scenes." She would like to hear from any family who has a child with a dual sensory impairment. Please leave a message for Molly with our Project Assistant, Nancy Lehr, at toll-free 800-360-7282, ext. 3115. You can also reach Molly directly by calling 412-863-1283.

NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND (NFADB): The National Family Association for Deaf-Blind is founded on the belief that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB is the largest national network of families who focus on issues surrounding deaf-blindness. NFADB can be reached at (800) 255-0411, ext. 275.

KIDS PAGE

Contributed by Stacy Gerlach

It's back to school! What a fun time . . . . and a stressful time, too! How are you (siblings) supposed to get your homework done with little brothers and sisters running around, especially when they don't understand that you have to get it done?? We put Billy (5 years) down to "play" in his ballpit in his room. It's part of his routine and it provides peace and quiet for Ashley (11 years), Ricky (9 years), and Bo (8 years) to get their homework done.

I found some support groups for siblings with multiply handicapped siblings:

PARENTS/SIBS SUPPORT GROUP
Butler Co. F.S.S.
112 Hillvue Drive
Butler, PA 16001
Linda Yetter
(412) 287-0791

SIBS ARE SPECIAL TOO
McKeesport Preschool for Special Children
5724 Smithfield Road
McKeesport, PA 15135
Carolyn Hay
(412) 751-9022

PARENT TO PARENT
1001 Brighton Road
Pittsburgh, PA 15233
Cathy Bonner and Marilyn Colosmo
(412) 322-6008

If you can attend any of these sibs groups, let us know how you liked it, what you liked best about it, or why you didn't like it.

My name is Bo Gerlach. I am 8 years old. I went to the Eagles Camp this summer with my family. We got our fishing rod. Last year in school, I got four good report cards.

Hello, my name is Ashley Gerlach. I am 10 years old and I had a great summer! These are some of the things I did . . . . . Eagles Camp, seashore, church camp, bible school, got a new pool, St. Mike's Faire, fishing party, Sesame Place, Chuck E. Cheese, and Pennsylvania Faire. This is what I did this summer!
(Ashley wrote her original submission in several differently-colored inks.)

Having a deafblind sibling, you probably know that they love to taste and smell things. Sometimes you don't know what you can do to really have fun with them . . . something that isn't boring for you. How about making some scented play dough?? Tell Mom it's even okay if you put it in your mouth, too!! Here's the recipe:

SCENTED PLAY DOUGH
1 cup flour
1/2 cup salt
2 tablespoons cornstarch
1 cup boiling water
1 tablespoon oil
6 drops food coloring
6 drops extract (like yellow/lemon or orange/orange, etc.)
Add dry ingredients (first 3) in a bowl. Mix.
Add the wet ingredients (last 4) in another bowl. Mix
Make a hole in dry ingredients. Add wet ingredients to it and mix with fork or spoon. Let the mixture set in the bowl in the refrigerator for a while, then share with sibs. Make all sorts of fun items with the scented play dough.

Well, this is it for now. Let me know if there is something special you want me to look into for you. **ASSIGNMENT FOR NEXT ISSUE**: Send me a photo or drawing of you or your family in your holiday outfit(s). Include a few lines about your favorite holiday. Be sure to label the photo with your name and age. The photos will not be returned. They will be added to the Project photo album (available for viewing at Family Retreats and Regional Days). Send it to: Kids Page, Stacy Gerlach, 39 Rambler Lane, Levittown, PA 19055.

ALERT!!

Anyone whose child receives medical assistance (ACCESS), be aware that things are changing! Beginning in January 1997, Managed Care Groups or HMOs will provide these benefits. The state has chosen five companies to provide service. If you are unaware of this, or need to know more, or need assistance in selecting an HMO, please contact your local county assistance office. A benefit consultant should be on site there from October 1996 and on to provide information and assist you in selecting a HMO. Check with your doctors to see which plan they are enrolled in.

Make your choice; don't let someone make it for you!

Contributed by Andrea Johnson, PA Parents for Deaf-Blind

➡ ➡ ➡ UPCOMING EVENTS FOR THE PA DEAFBLIND PROJECT ⬅ ⬅ ⬅

Annual Federal Deafblind Census	Statewide	Jan. and Feb., 1997
Advisory Council Meeting	Statewide	Feb. 5, 1997
Early Intervention INSITE Outreach Workshop	Pittsburgh	Feb. 14 and 28, 1997
Instructional Support System of Pennsylvania Statewide Conference	Grantville	March 18, 19, 1997
National Technical Assistance Consortium (NTAC) for Children and Young Adults Who Are Deafblind	Philadelphia	March 19-21, 1997
1997 Deafblind Project Family Learning Retreat	State College	April 11-13, 1997
Transition Team Partnerships Workshop	CISC, Harrisburg	May 29, 1997
National Conference on Deaf-Blindness	Washington, D.C.	June 6-9, 1997
Regional Family Learning Days	Southwest and Northeast PA	July 1997

Write or call us with your ideas and questions, or if you would like some assistance from the Deafblind Project.

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Glenside, PA 19038
(215) 884-1474

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39 Rambler Lane
Levittown, PA 19055
(215) 945-7364

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INFORMATION UPDATE (published quarterly)

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Call Nancy Lehr at the Project (800-360-7282) or mail to PA Deafblind Project, Attn: Nancy Lehr, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112-2764

INFORMATION SHEET

Considerations in IEP Development for Children Who Are Deafblind

by Mary R.Frey, M.Ed., Education Consultant, Pennsylvania Deafblind Project

> *The IEP(Individualized Education Plan) is a written plan that tells what special education program and services the child will receive.The IEP is written at a conference by a team which includes the child's parents. ...An IEP must include all the programs and services necessary to meet the child's individual needs as identified during the evaluation or re-evaluation process. (Mancuso, et. al., 1991, p.13.)*

Before the IEP meeting
Assessment is an on-going process of information gathering. When formal and informal evaluation results are reviewed, they identify the child's needs and strengths. The information is the base for future directions of the IEP goals and objectives.

With a younger child, the INSITE checklist or Callier-Azuza is helpful. A number of personal futures planning tools, such as the MAPS or PATH processes can also be used to gather information - history, likes/dislikes, skills/needs, etc. - about the child who is deafblind. Identification of how the child receives information, preferred learning style, and modes of communication are considered.

Parents need access to therapy reports and other evaluative information before the IEP meeting is held so they have time to read, absorb, and question. Holding a preplanning meeting or phone calls with the rest of the IEP team members may be ways for all to share equally in voicing their concerns about the child and answering questions about the child's current status. Parents need to consider what the priorities for learning are for the child. Make note of the areas that evaluators found difficult for the child.

During the meeting
Family participation is integral to the IEP process and parents are to be active members of the team. Family members are the child's primary teachers. The child should participate in the actual conference to the best of his/her abilities. When it is not feasible for the child to be present, having a photograph on the table can remind the team to stay child-centered during the planning process.

When the team meets to discuss and write an IEP for a child who is deafblind, the impact of the dual sensory impairments upon the child and upon the methods of communication and instruction must be recognized. Efforts to promote the use of existing hearing and vision while providing appropriate accommodations throughout the plan are important. The IEP is to be functional, relevant, and age appropriate to the child.

Based on the child's needs while building upon the child's strengths, the team drafts both annual goals and short term learning outcomes. While the educational team members may have brought along written goals and objectives that they would like to be included, these are just suggestions. Rather than asking parents if they agree or disagree with pre-written objectives, meaningful and appropriate outcomes are to be discussed while considering family concerns and priorities. The IEP process is to be a joint effort.

> *IEP objectives do not forget isolated skills written by individual specialists on the team (e.g., vision specialist, hearing specialists, occupational therapists). Instead, these team members, along with family members, pool their expertise to create one IEP that includes objectives that are activity-based and reflect the numerous skills required by the activity. The team needs to identify the various opportunities to practice targeted IEP skills across different functional activities. (Downing, 1996, p. 39, 41)*

Developing language and communication skills is the overall theme, in many cases, in developing an IEP for a child who is deafblind. In the earlier years of a child's program, time spent exploring and trying a number of communication options and establishing the foundation of a communication system is prevalent. In later years, the focus tends to be on expansion of the communication system and increasing interaction with friends and classmates. Environmental cues enhance the child's full understanding of various situations, whatever the child's preferred method of communication.

Parents can question staff about the teaching methods that work best for their child. The IEP addresses skills that promote both independence and interdependence. A multi-sensory approach in natural settings and environments is essential for successful achievement of integrated goals and objectives. Experiential learning strategies are employed since many incidental learning experiences are missed by the child who has dual sensory impairments Opportunities for repetition and practice of skills across a number of daily activities is very important.

Skills targeted in the IEP should be directly observable and measurable with specific criteria for success listed. Adaptations and accommodations are dictated by what the child needs to support participation in his/her program.

Supports (examples) to consider:
- *personal needs (feeding, medical, personal hygiene, dressing)*
- *physical needs (special equipment, environmental modifications)*
- *sensory needs (accommodations for vision and hearing needs)*
- *staff and peer education (how to communicate, what behaviors mean)*
- *provision of access and opportunities (extracurricular activities)*

(Huebner, et. al, 1995, p.117)

Once all the team members present at the meeting have shared information about the current functioning and skills of the child, drafted goals and learning outcomes, agreed upon related services and accommodations to support the child in his/her IEP program, they sign the IEP form indicating their participation in the development process. *(See Mancuso for further details.)*

After the meeting

The IEP is considered a working document. It is to be reviewed annually by the IEP team and changed when needed. Ongoing communication between families and school staff about what and how the child is learning is important.

✎ *This information sheet briefly discusses considerations for IEP development for a child who is deafblind. If you would like more information, you may contact the Pennsylvania Deafblind Project.* ✎

References

Downing, June E., Ph. D. (1996). Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers. Baltimore, MD: Paul H. Brooks Publishing Company.

Huebner, K., Prickett, J.G., & Welch, T.R., Joffee, E. (eds.). (1995) Hand in hand: Essentials of communication and orientation and mobility for your students who are deaf-blind. New York, NY: AFB Press.

Mancuso, E., Rieser, L., & Stotland, J.F. (1991). The right to special education in Pennsylvania: A guide for parents. Philadelphia, PA: The Education Law Center.

The Pennsylvania Deaf-Blind Project

Information Update

Summer 1996

The purpose of this Information Update is to describe project activities and to share ideas. Please pass this update on to other families or colleagues who might be interested.

WHAT CAN A FAMILY CONSULTANT DO FOR YOU??????

contributed by Ellen Blackburn, PA Deaf-Blind Project Family Consultant

There are many ways a family consultant can help you.

At your last IFSP (Individual Family Service Plan) or IEP (Individualized Education Plan) meeting, did you feel as if you were on a different page than every one else? Did you want to talk to somebody about it? You could talk with a family consultant.

Do you have questions that you are not sure where to get the answers? Maybe a family consultant knows where you can get the answer. Maybe a family consultant can find someone who does know the answer.

Are you interested in networking with other families that are in your area? Are you interested in starting a local support group? A family consultant can help.

Are there topics you would like to see addressed in this newsletter? At the family weekends? At a regional learning day? Let a family consultant know. Of course, you can call the project directly.

The family consultant's overall purpose is to assist the PA Deaf-Blind Project in addressing your needs. Let us know what they are.

(Ellen can be reached directly at 610-884-1474. To save on your long-distance phone cost, feel free to call Nancy Lehr from the PA Deaf-Blind Project at 800-360-7282, and ask for Ellen to return your call). (Please refer to last page of this newsletter for addresses of our family consultants.)

The next issue of our newsletter will focus on Individualized Education Plan (IEP) and Individual Family Service Plan (IFSP) issues. A list of resources will be included specific to these issues.

QUESTION: What are your experiences -- positive or challenging -- in regards to addressing your child's deaf-blindness in the IEP/IFSP?

Call Juli or Mary to share your experiences, or send us a note. We will include what we learn in a helpful way in the Winter issue of this newsletter. Thank you.

FAMILY LEARNING AWARD

Molly Black, one of our family consultants, recently received a Family Learning Award to support her family's attendance at Pennsylvania Chapter meeting of the Cornelia deLange Syndrome Association. She is willing to contact other families of children with Cornelia deLange Syndrome and share what she has learned.

Family Learning Awards are available to assist families to improve the effectiveness of education and interactions for the child who is deaf-blind. Once an award is used, the family is expected to share with other families, through the project, the impact of that award on the child who is deaf-blind and the family. Materials about the Family Learning Awards are enclosed with this newsletter or may be received by calling Nancy Lehr (1-800-360-7282).

ONE MOM'S INTRODUCTION TO INCLUSION

contributed by Molly Black
PA Deaf-Blind Project
Family Consultant

Sometimes I feel like I'm the last one to jump on the bandwagon. Just when I feel comfortable with a new fashion, it quickly goes out of style. Inclusion is a bandwagon I have yet to jump on completely. As parents of children with disabilities, we all have faced or will face that all important question: Is inclusion a good thing for my child? Well, I have to admit, so far I've kept my child, Alex, who is dual sensory impaired due to Cornelia de Lange Syndrome, in a very segregated, educational environment. At the same time, I've been known to advocate for inclusion. I've been talking the talk, but have yet to walk the walk, as they say. I do believe in my heart it is right. At the same time I'm torn because of my child's incredible needs. My overall feeling, of course, is to keep choice of placement open to parents.

Facing this summer without a program, and knowing all too well that the Pennsylvania government expects me to lean on my community more for resources, Alex and I set out to test the waters. We set our sights on Bible School. Before we started, I explained our situation and offered to accompany Alex as his aide on this grand adventure. The first decision we faced was whether I wanted him to be included with children his own chronological age or his developmental age. We quickly decided to stay with children his own chronological age since these were the children in the neighborhood most familiar with him.

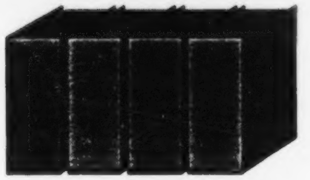
My husband warned me not to be too disappointed if the week did not turn into this wonderful "inclusion" story that would convince me wholeheartedly that inclusion is a good thing for my child. Throughout the week I was asked many questions by the children such as "Why doesn't he talk?" and "Does he have a disease?" However, I saw many more heartwarming situations such as one little boy who took Alex's hand while they were swaying to music, and the three little boys who fought over who got to sit next to him.

I'd like to add that my story almost ended without any great revelation one way or the other regarding inclusion. However, we were saved in the "Nick" of time. It was saved by a little boy named Nick who took a particular liking to another little boy, named Alex. Never mind that Alex never sought him out, talked to him or even interacted very much with him. On the very last day in the very last hour of our time spent together, Nick came to me and asked whether he could come over to Alex's house to play with him sometime. Thank you, Nick, for making our first real attempt at inclusion a "good thing."

(Molly can be reached at 412-863-1283. To save on your long-distance phone cost, feel free to call Nancy Lehr, Project Assistant, at 800-360-7282, and ask for Molly to return your call).

TIP
"I put my son, George, in a large clothes basket when we are in the basement near a lot of "no-no's'. I give him a few toys and he's occupied while I load and empty the washer and dryer."
Marcella Zielinski

➡ **Hand in Hand Study Groups**
Two upcoming Regional Family Learning Days (September 7 and October 19) mark the beginning of an effort to link parents and their children's teachers in study groups, using newly published materials. Hand in Hand, published by the American Foundation for the Blind, is a set of materials focusing on communication and orientation and mobility for children and youth who are deaf-blind. Please call the Project if you are interested in forming or joining a study group.



RESOURCES AVAILABLE

The PA Deaf-Blind Project has resources available for loan to families and others. Please call the Project if you would like to borrow these items, or are interested in resources on other topics:

It Isn't Fair: Siblings of Children with Disabilities includes first-hand perspectives of siblings, from over twenty years of selections from *Exceptional Parent* magazine, parents' thoughts, and comments and guidance from the editors (copyright 1992, from Exceptional Parent Press).

Nobody's Perfect: Living & Growing with Children Who Have Special Needs is written for parents, and offers strategies and support for situations that parents of children with disabilities face in their everyday lives (copyright 1994, from Paul H. Brookes Publishing Co.).

Taking Charge: Teenagers Talk About Life and Physical Disabilities is based on information obtained during interviews with teen-agers. This book covers three major areas: the individual and self-esteem; relationships with family, friends, and community; and future long and short term goals, and how to achieve them (copyright 1992, Woodbine House).

A list of the titles of books, manuals, and videotapes in the PA Deaf-Blind Project Resource Directory is available. We have ordered more materials to add to our resources. The list is long and includes only the titles. We will feature different materials in more detail in upcoming issues of this newsletter. You may call Mary or Juli if you have questions about the resources. Most are available for a one-month loan.

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Introducing Stacy Gerlach and the "Kids Page"

Stacy, one of three family consultants for the PA Deaf-Blind Project, is the very busy mother of four children. She, her husband Rich, and children live in Levittown near Philadelphia. Billy, five years old, will begin school in Bristol Township.

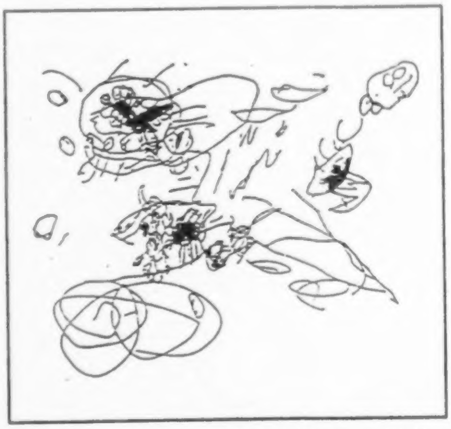
Stacy can support other parents of children and youth who are deaf-blind through phone consultation, referrals, and other activities. She will be maintaining a "Kids' Page" in this newsletter, so please send her any information about recent events in your children's lives, tips, etc. We would especially like drawings (black and white would copy best), notes from brothers and sisters, and celebrations of your child's successes. Stacy writes: **This is our new "Kids Page". We're looking for authors. Tell us about your summer. Did you go somewhere exciting? Did you do something you never did before? Let us hear from you!**

Stacy can be reached at (215) 945-7364. In order to save you long-distance charges, you can also call Nancy Lehr at (800) 360-7282 and ask her to have Stacy call you back.

TIP
"Videotape your child doing various activities, i.e., mealtimes, sibling play, family outings, and activities of daily living skills. This will serve as a resume for your child."
Cynthia Jackson-Glenn.

➡ Special Kids Network

The "Special Kids Network" is a new toll-free call-in service (1-800-986-4550) that helps families locate a broad range of health care information and other services. It is a statewide information service for families with children with chronic health problems and disabling conditions.



"The dream I want to catch is full communication with others."
drawn by Morgan, age 4

Brothers and Sisters at the PA Deaf-Blind Project Family Learning Retreat

Dr. Sheri Moore, a professor at the University of Louisville in Kentucky, spent time with siblings at the recent Family Retreat while siblings made "dream catchers". They talked about their dreams for themselves, and for their brother or sister who is deaf-blind. The loving wisdom of the young came through so loudly, as when one sibling said, " I want him to be independent, to do certain things for himself. But I want for him to be around us."

Sheri talked about the potential of a process called "Person Centered Planning" (PCP) with the families at the retreat. PCP allows a group of people who are close to a person to dream and visualize future successes, and then to work out an action plan to achieve those successes. We practiced this process with families at the retreat, using different strategies. Sheri said that the value is in surrounding yourself with a circle of support. "When we look at the future with a systematic approach, it's easier to get to where you want to go."

Sheri also summarized her experience with the siblings at the Family Retreat. She noted that siblings think a lot more about their brother or sister who is deaf-blind, than we might realize. She recommended that parents talk with their children about their concerns on a regular basis and as things naturally occur. Sheri pointed out that it is a good idea to start thinking about these issues early. Parents might not have all the answers, but the door to communication will always be open.

IN FUTURE ISSUES, WE WOULD LIKE TO DEDICATE THIS ENTIRE PAGE TO "KIDS PAGE"

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WHAT'S HAPPENING FOR THE PA DEAF-BLIND PROJECT

Eastern PA Regional Family Learning Day	Overbrook School for the Blind	September 7, 1996
Advisory Council Meeting	PennTech, Harrisburg	September 24, 1996
State and Local Transition Team Workshop	PennTech, Harrisburg	October 8-9, 1996
Western PA Regional Family Learning Day	Sharon-Hermitage Holiday Inn	October 18-19, 1996
Early Intervention INSITE Outreach Workshop	Pittsburgh	October 18 and November 8, 1996
Teleconference: What are all these adults doing in my classroom?"	Downlink sites available across PA	November 19, 1996
PennTech Assistive Technology Exposition	Various locations	December 3-6, 1996
Early Intervention INSITE Outreach Workshop	Pittsburgh	Feb 7 and 14, 1997
State and Local Transition Team Workshop	PennTech, Harrisburg	March 1997
1997 PA Deaf-Blind Project Family Learning Retreat	State College	April 11-13, 1997
National Conference on Deaf-Blindness	Washington, D.C.	June 6-9, 1997

For more information, call the Deaf-Blind Project at 800-360-7282

➡ Early Intervention Outreach Project

On June 24, 25 and 26, a very enthusiastic group of early intervention service providers and parents began a pioneer step in outreach efforts to support very young children with sensory impairments. The first day of the workshop focused on exploring the variety of ways adults learn. The second and third days focused on three curriculum models for children and how to support training at the local level. As a result of this workshop, Pennsylvania has a pool of people who can assist local agencies in INSITE training, and network with and support one another.

The INSITE model is an early intervention approach with a focus on helping families enhance the development of their children who are deaf-blind, or who have multiple and sensory impairments. A local workshop is planned for this fall in the Pittsburgh area. If you would like to inquire about local INSITE workshops in your community, please call Juli Baumgarner or Mary Frey.

➡ NICHCY

The National Information Center for Children and Youth with Disabilities is an information clearinghouse that provides information on disabilities and disability-related issues for children and youth (birth to age 22). Anyone may contact NICHCY for a publication list and information at 1-800-695-0285 (voice/TT) or 1-202-884-8441 (fax).

••••••••••• DID YOU KNOW? •••••••••••

In the 1996 Summer issue of the Millersville University Review was the following interesting fact. "Pennsylvania has the largest rural population in the United States with nine million acres of farmland, nearly one-third of the total area of the state."

Write or call us with your ideas and questions, or if you would like some technical assistance from the Deaf-Blind Project.

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This publication is available in alternative media on request. PennTech is an equal opportunity employer.

The Pennsylvania Deaf-Blind Project

Information Update

Spring 1996

Educational Consultants
Juli Baumgarner
Mary Frey

Parent Consultants
Ellen Blackburn
Stacy Gerlach
Molly Black

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Project Update

We are growing! Last year, Pennsylvania was awarded a four year federally-funded grant to provide training and technical assistance to families, educators, and service providers of children and youth who are deaf-blind, between the ages of birth and 21 years. This information update is intended to describe some of our activities.

Two full-time educational consultants -- Juli Baumgarner and Mary Frey -- coordinate the project. Three part-time parent consultants -- Ellen Blackburn, Stacy Gerlach, Molly Black -- assist. Nancy Lehr is our office coordinator. Additionally, other parents -- Miriam Roberts, Lydia Berger, Cynthia Jackson-Glenn -- provide assistance in specific activities. We collaborate with our colleagues from the Instructional Support System of Pennsylvania and PennTech.

Children and Youth who are Deaf-Blind

Over the past six years, there has been a dramatic increase in the number of identified children and youth who are deaf-blind in Pennsylvania. Through collaboration with staff at early intervention agencies, the identification of the infants and toddlers who are deaf-blind or are at risk for deaf-blindness increased. As of 1996, there are 571 identified children and youth who are deaf-blind. This number is consistent with the statistics for Pennsylvania's population of students receiving special education. Parents, teachers, therapists, school nurses, and administrators have assisted the Project in identifying these children and youth by completing Deaf-Blind Census forms; these are updated on an annual basis.

Six years ago, we identified only 84 individuals between birth and 21 years of age who are deaf-blind. At that time, we did not have an educational consultant living and working in Pennsylvania. Instead a multistate deaf-blind project provided technical assistance. Later, funding was obtained to hire one educational consultant. Since 1995, we have been funded for two educational consultants, and three part-time parent consultants to work in the PA Deaf-Blind Project.

Project staff plan training workshops based on census information and identified needs. The identified children and youth extend across all age groups, in a variety of educational settings, with differing skills and abilities. We know that almost half of the children who are deaf-blind are between birth and six years of age.

Parent Consultants

Three parents of children who are deaf-blind provide support and information to other parents, and help the Project develop and provide training. Our parent consultants include Ellen Blackburn, Stacy Gerlach, and Molly Black. They can be reached by calling our project assistant, Nancy Lehr, at

> *"I feel I have a better understanding of and compassion for the parents."*
>
> *INSITE participant*

(800) 360-7278, and requesting a contact. Parent consultants have made parent-to-parent contacts, have been involved in setting training and workshop agendas, such as for the Family Learning Retreat, and have provided training at early intervention workshops. We are enriched by their experience. As one of the parent consultants said, "Sometimes a parent is part of the team in name only. However, when a parent brings knowledgeable information to the table, she becomes part of the team."

Technical Assistance

One of the most important functions of the PA Deaf-Blind Project is to work with local teams of educators, service providers, and families to help plan for the intervention or education of children and youth who are deaf-blind. Our educational consultants use phone conferencing, videotape exchanges, and on-site visits to work with local teams. Some of the areas that we have visited since October 1995 include Philadelphia, Pittsburgh, Bensalem, Oil City, Williamsport, Mansfield, Lebanon, Mar Lin, Lancaster, New Castle, Pennsylvania School for the Deaf, and Overbrook School for the Blind.

Some of the activities include helping to develop behavioral support plans, visiting classrooms to help design communication and activity plans, and meeting with teams to focus on educational goals and strategies. The project also has supportive resource materials, such as relevant books, articles, and videotapes available for loan to families, educators, and service providers. Technical assistance or parent-to-parent contact can be arranged by calling Juli Baumgarner or Mary Frey at the 800 number.

Early Intervention

In collaboration with the Family Focused Early Intervention System (FFEIS), the Deaf-Blind Project has provided a six-day INSITE curriculum workshop to families and service providers. Over 300 people have completed this training, which is intended to help families enhance the development of their infants, toddlers, and young children who are deaf-blind. A participant in a recent workshop wrote, "I feel I have a better understanding of and compassion for the parents after being involved with this program."

Previously only offered regionally, in response to requests by communities we are currently extending this model to more local sites. We are seeking parental involvement with the training as it becomes available in local areas. Our parent consultants and our Pennsylvania INSITE trainers assist the Deaf-Blind Project in planning for and providing training in communities or at agencies.

We are offering a training workshop on June 24-26, 1996, to help families and service providers learn about and implement the INSITE curriculum. The people who attend this workshop will be our main points of contact as we plan further INSITE training. Also attending the June workshop will be participants who will learn about other curriculum and service delivery models that may benefit children who are deaf-blind.

Transition

In late 1992, we were awarded a grant from the Helen Keller National Center-Technical Assistance Center (HKNC-TAC) to begin a state and local team partnership. This interagency model is to enhance the transition from school to adult life of youth who are deaf-blind. HKNC-TAC has provided valuable training and guidance, and also helped to sponsor some of the costs involved.

We formed a State Transition Team for Individuals who are Deaf-Blind in January 1993, and continue to meet and identify a number of transition issues for students over 14 years old who are deaf-blind. The State team is made up of parents (previously Donna Nelson, and now Lydia Berger), representatives from: Blindness and Visual Services (BVS), the Developmental Disabilities Planning Council, the educational transition project (PAL), schools (Overbrook School for the Blind), PA Deaf-Blind Project staff members, and others. Our State team supports the local teams by participating in local team meetings, and providing annual workshops.

Local teams are built around at least one student and use a case study approach. Local teams have been formed in Pittsburgh, Reading, Schuylkill County, Philadelphia, and at Overbrook School for the Blind. We are planning to form several new local teams and are searching for interested persons. Call Mary or Juli for more information.

We have learned about the needs of students who are deaf-blind from our local teams, and have brought issues to the attention of state level entities. For example, while BVS is the lead agency for vocational planning for individuals who are deaf-blind, we have found that many students might be served by other agencies that can meet their needs. Because the state and local teams are made up of many different representatives, people have a chance to learn about potential services that each agency or project might provide for an individual. We have also developed a booklet entitled, "Quality Indicators of Community Employment and Training Programs."

Recently a group of state and local team members attended a workshop sponsored by HKNC-TAC. Lydia Berger (parent), Cynthia Jackson-Glenn (parent), Dael Cohen (Overbrook School for the Blind transition coordinator), Carol Patterson (Berks County MH/MR case manager), Juli Baumgarner (PA Deaf-Blind Project), and Mary Frey (PA Deaf-Blind Project) attended the workshop with teams from other states, and shared experiences and learned new information.

Cynthia Jackson-Glenn facilitated a session at the workshop on parental involvement in the transition process, saying, "(My daughter) has a plan. We're talking about housing, about communication, about the community. She's come a long way. We have a team—everyone can present their ideas. It opens the door to many things. Professionals need to be open minded, because things don't always go the way they're taught."

Usher Syndrome Task Force

A task force was formed in 1995 to address concerns around students with Usher Syndrome. This syndrome is a cause of deaf-blindness that begins with deafness or hearing impairment, and involves a gradual loss of vision. Consumers, family members, adult service agency representatives, educators, and PA Deaf-Blind Project staff have identified goals to support students in the educational process, and to establish systematic screening for the progressive vision loss associated with Usher Syndrome. The task force planned and presented a video teleconference, "When Retinitis Pigmentosa and Hearing Loss Happen Together: Meeting Educational Needs." The teleconference was broadcast to 15 states and many downlink sites in Pennsylvania on March 5, 1996. The PA Deaf-Blind Project is following up on technical assistance requests which resulted from the teleconference, such as conference presentations, materials loans, and meetings with students' educational teams.

Behavior Support Core Team

The PA Deaf-Blind Project represents concerns of children and youth with sensory impairment to the state interagency Behavior Support Core Team.- The team meets periodically to develop and share information regarding training and resources in Pennsylvania for students with behavioral support needs. Juli Baumgarner recently presented a session at the Pennsylvania Conference for Educators of Persons with Visual Impairment entitled

"Learners with Unconventional Behavior" and is working with some of the teachers who attended the session.

Family Learning Retreat

The annual Family Learning Retreat was held on May 31, June 1, 2, 1996, in Harrisburg. Jointly planned by staff and parents, the focus of the weekend was on catching dreams and the steps to make these dreams a reality for children who are deaf-blind. Child care was provided by staff from Overbrook School for the Blind. Artists and musicians involved all the children in projects. A number of consultants shared information and involved parents during workshops.

Conferences

Mary Frey and Juli Baumgarner present information and train educators, service providers and parents throughout the year at conferences, teacher inservices and on-site visits. They also attend professional conferences and share what they learn. Juli and Mary will be presenting a session, "Accommodations for Students With Sensory Impairments", at the Instructional Support System's annual conference.

Mary recently participated in an international conference on deaf-blindness, "Living and Learning: A Lifelong Adventure."

Future Plans

Two learning days for families are planned for summer/fall -- one in the eastern region of PA and the other in the western region of PA. Topics are being discussed by the planning committee of parents and staff. Details to follow.

Please send us information that we can share through our "Information Updates". We plan on publishing this information update quarterly. We welcome any first-person stories... for example: about an experience with a child who is deaf-blind; a strategy that worked at home, school, or community; a communication method. In our next issues, we will highlight our parent consultants.

Write or call us with your ideas and questions, or if you would like some technical assistance from the Deaf-Blind Project.

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